THE CITIZENS PANEL ON INCREASING ORGAN DONATIONS

Seeking views and opinions on increasing organ donations in Ontario

REPORT OF THE CITIZENS PANEL ON INCREASING ORGAN DONATIONS

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COMITÉ DES CITOYENS POUR L'AUGMENTATION DES DONS D'ORGANES

Connaître les points de vue et les opinions pour augmenter les dons d'organes en Ontario

Dr. Ted Boadway
Chair

Alvin Curling
Peter Desbarats
Rev. Brent Hawkes
Gisèle Lalonde
Joan Neiman

Secretariat
Janet Napper
Doreen Thibert

March 2007

The Honourable George Smitherman
Minister of Health and Long-Term Care and Deputy Premier
Hepburn Block, 10th Floor
80 Grosvenor Street
Toronto, ON M7A 2C4

Dear Minister Smitherman:

As members of the Citizens Panel, we are pleased to submit our report, which contains our advice and recommendations for increasing organ donations in Ontario.

Our report reflects the views and opinions of Ontarians that we heard through public meetings and discussion groups in communities across Ontario from November 06 to February 2007, meetings with interested groups and individuals, and more than 2,000 responses to our survey on organ donation issues.

Today in Ontario, the need for organs far exceeds supply. Currently more than 1,750 people in Ontario are waiting for life-saving organ transplant surgery, underscoring the continuing need to increase organ donations. Every three days, someone in Ontario dies waiting for a transplant. During our consultations, we clearly heard that Ontarians find it unacceptable that patients are needlessly suffering and dying while on the waiting list.

The Panel shares their urgency. Our recommendations focus on improving awareness of the importance of organ donations, removing barriers to donation, improving how people can express their donation preferences and register their consent to donate, and how the Ontario government can support and encourage more living organ donations.

We commend your vision as Minister of Health and Long-Term Care in creating the Citizens Panel to hear the views and opinions of Ontarians on this extremely important issue. The people of Ontario, who make the decision whether or not to donate, are the most important players in the system. We believe Ontario needs a transparent system that makes people's wishes known, registered and respected. An effective data base, available round the clock, will make those wishes known to hospitals and transplant teams at the proper time. Public education about this new system will increase people's confidence in the organ donation system by guaranteeing respect for their wishes.

We thank you again for providing us with a real opportunity to improve Ontario's system of organ donation and provide more Ontarians on waiting lists with a new chance at life. We welcome your consideration of our report and look forward to the timely implementation of our recommendations.

Sincerely,

Ted Boadway

Dr. Ted Boadway (chair)
The Citizens Panel on Increasing Organ Donations

Executive Summary

Organ donations save lives. For years, Ontario has worked to make the system of donation more effective. Yet those with the most important role, the citizens of Ontario who make the vital decision to donate or not donate organs, have never been asked their opinions on this vital issue.

With that in mind, the Honourable George Smitherman established a Citizens Panel to hear the views and opinions of Ontarians on organ donation. In preparing its report, the Panel consulted widely with Ontarians, met with experts, and reviewed previous reports on improving organ donation and transplantation.

The Need

Ontario has a critical need for transplant organs. Today, more than 1,700 Ontarians are waiting for an organ transplant. Since 1994, Ontario's transplant waiting list has increased by two-thirds. These patients are very ill. Most are too sick to work. Unfortunately some die while on the waiting list..

Millions of Ontarians carry an organ donor card. They believe this will guarantee their donation wishes will be respected in death. They were shocked to learn that donor cards are almost never seen or asked for, that the family's decision will prevail even if it contradicts the deceased's wishes, and that organ transplantation teams cannot get OHIP organ donation preference information, even though this is permitted by law.

The Panel recommends:

- The clause in Trillium Gift of Life Act which allows exemption to consent be amended to require tangible proof of withdrawal. (pg. 5)
- Some government forms, such as the OHIP card renewal, require Ontarians to state their organ donation preferences. (pg. 5)
- A central database record these preferences. (pg. 5)
- This information be sent regularly to the Trillium Gift of Life Network, which will make it available to families and appropriate health care providers at the appropriate time. (pg. 5)

Education

Ontarians are misinformed about organ donation. To correct this and help increase organ donations, the Panel recommends:

- A public education campaign be developed assuring the public their wishes will be respected and informing them how this will be done. (pg. 7)
- The existing school education program, *One Life...Many Gifts*, be piloted in other Ontario school boards, including Francophone boards. (pg. 7)

- Consideration be given to creating a youth-oriented website and other programs about organ donation. (pg. 7)

The Role of Religion
For many Ontarians, religion strongly influences their decision whether or not to donate. While all major religions officially permit organ donation, many Ontarians said their faith leader had spoken against it.

The Panel recommends:

- The Ontario government bring together a committee or conference of religious leaders to consider engaging religious schools in organ donation and implementing a program which sees religious communities throughout the country observe a National Donor Sabbath in the same week every year. (pg. 8)

Availability of Organs
The Panel examined the three sources of organ donations: donation after brain death (DBD), donation after cardiac death (DCD) and living donation.

Donation after brain death is a major – but limited – source of organs. Less than 1% of Ontarians who die in hospital each year meet the strict DBD criteria.

Donation after Cardiac Death
The number of additional organs DCD would contribute is difficult to ascertain, but estimates are that it could increase the number of donations by up to 25%.

The Panel recommends:

- Every hospital in Ontario that provides donors should institute DCD policies consistent with the National Recommendations. (pg. 14)

Living Donations
Living donations are most common for liver and kidney transplantation. Yet living donors often face unanticipated economic hardship in donating. To address this, the Panel recommends:

- The Ontario Government enact legislation to ensure living donors are guaranteed job security. (pg. 16)
- A fund be established to pay for reasonable pre-approved expenses and lost wages. (pg. 16)
- The Northern Health Travel Grant program be extended to living organ donors and potential donors. (pg. 16)
- A province-wide database of living donors and unmatched recipients be housed at the Trillium Gift of Life Network. (pg. 17)

In the Hospital
Three key areas must be addressed: the experience of donor families, hospital-specific issues, and the intensive care unit.

Supporting Donor Families
Many families deny hospital requests to retrieve organs from their loved one based on an emotional reaction at the time of death. This underscores the clear need for medical and nursing staff to communicate skillfully and effectively with families about organ donation. To help donor families, the Panel recommends:

- Hospitals consciously select the team which will support families of potential donors in the time of crisis. These teams should themselves be supported with continuing education and case review. Trillium should be engaged to provide consistency and excellence in training. (pg. 19)
- A conference – or several regional conferences – of volunteer support groups should be held to enhance mutual learning and to examine duplicating models across the province. (pg. 19)

Hospital-Specific Issues
Canadian hospitals must pay the reasonable costs of retrieval when they accept an American organ, yet do not charge American hospitals for Canadian organs.

The panel recommends:

- The Ministry of Health and Long-Term Care should provide Trillium with a fund to reimburse reasonable costs to American hospitals for the purchase of U.S. organs. (pg. 20)
- Trillium should be allowed to collect reasonable costs from American hospitals for Canadian organs. These costs should mirror American costs. (pg. 20)

Critical Care
Ontario has a shortage of intensive care beds. While a Critical Care Strategy is under way, organ donation is not part of the planning for critical care resources.

The panel recommends:

- The Critical Care Strategy should include organ donation in the planning and consideration of resources needed for an increase of donors to more than 300 per year and widespread use of DCD. (pg. 21)
- The Critical Care Strategy group should work with the Trillium Gift of Life Network to develop processes and protocols. (pg. 21)

The panel learned that intensivists undertake a range of demanding tasks in the transplant process, many of which are not paid for under OHIP.

The panel recommends:

- A special study of intensivists' compensation for donor management be commissioned and the results used to advise the Ministry of Health and Long Term Care and the Ontario Medical Association, in future determination of fees. (pg. 22)

Accountability Agreements
Ontario's 14 Local Health Integration Networks (LHINs) sign accountability agreements with the Ministry of Health and Long-Term Care. The Panel believes the Minister should place strong emphasis on organ donation within these agreements and recommends:

- The Ministry of Health and Long-Term Care include organ donation in its accountability agreements with the LHINs, beginning with the 2007-08 fiscal year. (pg. 23)
- Each LHIN should strike an accountability agreement with its hospitals which reflect the provincial priorities for organ donation. (pg. 25)
- LHINs cooperate with and use the Trillium Gift of Life Network for education and as their common source of knowledge and a common database on transplant matters. (pg. 25)

Trillium Gift of Life Network
Ontarians said they are confused by the name Trillium Gift of Life Network, saying it provides no clue as to the purpose of the organization.

The significant increase in responsibilities and mandate recommended by this report will require the Trillium Gift of Life Network to be given additional resources.

The Panel therefore recommends:

- Trillium be allowed to change its name to something less likely to lead to misunderstanding and in accord with its mandate. (pg. 25)
- Sufficient resources be allocated to Trillium to carry out its new mandate under the Panel's recommendations. (pg. 26)

The Panel notes that some issues, such as paired exchanges, are best addressed on the largest scale possible. The Panel therefore recommends:

- Whenever practical and beneficial, Ontario cooperate with other provinces to the fullest extent in developing approaches and systems to support organ donation. (pg. 26)

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1 Introduction

Organ donation is a vital method of saving lives. For years, the health-care system has been perfecting techniques and procedures to improve the effectiveness of organ donation, but the most important players in organ donation are the people of Ontario.

They make the only decision that matters: whether to donate. This is the pivotal decision that determines whether hospitals and transplant teams have a treatment to carry out or not. And yet, the people of Ontario had never been asked their opinions on this matter.

With this in mind, the Honourable George Smitherman, Minister of Health and Long-Term Care, established a Citizens Panel (Appendix 3) to reach out to the people of Ontario through a variety of means to determine what they think about organ donation. (Appendix 4) The Panel found the Minister's inclination well grounded. Ontarians do have opinions about organ donation, and they want those opinions heard and heeded. The thoughtfulness and wisdom of these comments led Panel members to commit themselves – individually and collectively – to giving form and substance to those sentiments. This report to the Minister is the Panel's effort to do just that.

In our consultations, we discovered that people already had well-formed, laudable opinions and goals on some donation issues. But we also saw the anger and dismay of those same people when they were told that the reality did not live up to their expectations. The Panel understood how people had developed these ideas and how the realities had let them down. It became the Panel's objective to realign these realities so they fit with the laudable goals Ontarians expressed.

The Minister also asked the Panel to review our own present system, other systems and previous reports to identify any improvements that could be made. The Panel discovered anomalies and misalignments in our present system, as well as the hopeful beginnings of new changes which the Panel recommends the government fully embrace to better meet the donation need.

2 The Panel's Methodology

The Panel reached out to Ontarians in several ways. We held public meetings in communities across Ontario and when the pre-holiday season reduced attendance, we added a further series of meetings in the New Year. This resulted in good response to the 45 public meetings we held. (Appendix 5)

We also held 29 discussion groups in order to get the views of particular communities and religious and cultural groups. The Panel found that in the discussion groups almost all attendees were not personally attached to the issue of organ donation. This contrasted sharply with the public meetings, at which many attendees were strongly attached to the organ donor issue. Some were recipients or donors, others were awaiting transplant, or were health professionals involved in transplant.

By conducting both public meetings and discussion groups the Panel was able to reach out to all the people of Ontario. (Appendix 6)

We also used surveys – both on-line and mailed out. The mail-out involved thousands of surveys sent through community groups and the offices of Members of Provincial Parliament. More than 2,000 were completed and returned. (Appendix 7)

The Panel also met with – and received deputations from – Ontario, Canadian and international experts in the field. (Appendix 8)

Finally, the Panel reviewed previous reports made in Ontario and across Canada which examined how to improve organ donation and transplantation. While the Panel found these reports to be amazingly consistent over the decades, alarmingly, it also found that their recommendations were seldom implemented. (Appendix 9)

The Panel has used this wealth of information to come to some conclusions on elements that need to be fixed and on areas where innovation is required.

After a brief description of the need, this report will describe the expectations of Ontarians and how the system can be aligned with those expectations to everyone's benefit. Then, the report will review what can be done within the health-care system itself to maximize the retrieval of organs to increase the number available for life-saving therapy.

3 The Need

Following is a brief review of the critical need for organs for transplant. It provides context to the discussion and direction of this report.

The Trillium Gift of Life Network is the not-for-profit agency responsible for coordinating and supporting organ donation. Trillium reports that there are 1,700 people in Ontario waiting for an organ transplant. Of these, 1,150 need a kidney while the rest need liver, lung, heart, pancreas or bowel transplants.

These numbers are growing. Between 1995 and 2005 the number of people on the waiting list increased by two-thirds. The leading edge of the Baby Boom generation has provided an inexorable demographic drive that has increased the number of people who need transplants.

Further complicating the matter is the spectacular success of organ transplantation. Many can remember the time when transplants only survived a year. Today, however, survivals of 10 and 12 years are the norm, and the survival of transplanted organs for more than 30 years is not rare. Doctors are performing transplants today they would not have attempted a decade ago. Better patient management has allowed surgery on those previously excluded from transplant consideration. Furthermore, the gradual realization that age is not a barrier to transplantation has meant that some very-much-older patients can now benefit from transplant. At one time people older than 45 were not considered for transplant surgery.

These statistics tell only part of the story. Patients on the waiting list still are very ill. Most are too sick to work and often require significant care-giving from family members. Consider: Whereas dialysis may support patients with kidney failure for years, it does not restore people to health. People waiting for other organs often live with the crushing burden of knowing that if they don't receive a transplant, death is the probable outcome. Indeed, people do die while on the waiting list.

Even the numbers currently on the waiting list do not reflect the true magnitude of the need. Experience elsewhere has shown that if more organs were available, more people would be put on the waiting list as physicians began to apply for patients who do not fit exactly the criteria for organ transplantation.

Our consultations have shown that Ontarians find it unacceptable that patients are dying while on the waiting list. The Panel shares their sense of urgency. Simply put, increasing the number of organs available for transplant will reduce the needless suffering of thousands of people across Ontario.

4 Impressions, Beliefs, and Expectations

Ontarians told the Panel they know that millions of Ontarians carry a card indicating their wish to donate organs in the event of their death. The most common is the OHIP card, but other valid cards also exist. During the Panel's meetings, people would reach into their wallets and pull out a card to confirm they had one. They told the Panel they believed that in the event of their death, this card would carry weight and insure that their wishes would be carried out.

However, when the Panel told these people that, in fact, the cards are almost never requested, or even seen in the hospital, their reactions ranged from dismay to anger to bitterness. These people believed they had done something of value in signing their card – only to discover that this was an illusion and that their wishes were unlikely to be acted upon.

When the Panel further explained that rather than checking the card, the hospital would consult the family and that the family's decision would prevail – even if it were counter to the deceased's desires – the reactions ranged from incredulity to rage. One man wanted to know why, if his instructions about his property surely would be carried out on his death, he couldn't be guaranteed the same thing for himself. One woman said – with some humor, but even greater intensity – that she had told her children that if they didn't honor her wish to donate, she would come back to haunt them.

Both in discussions and in survey results, the position of Ontarians was unanimous – they want their wishes respected and overridden by no one.

Ontarians also told the Panel they believed something useful happens with their information once they sign their card. They were informed that, indeed, if they have it on their OHIP card, the information is stored in an OHIP database in Kingston. However, once there, the information is kept secret. Even though the law allows OHIP to give out this information to the appropriate people

at the time of death, it never is. Ontarians responded to this information with anger, calling the process a "sham". The Panel concurs.

How did Ontario arrive at this state? The law provides some answers, a way of understanding the current state, and a basis for the repair and implementation of the new system the Panel is proposing.

5 The Law

The Trillium Gift of Life Network Act clearly states that a person's consent is binding and gives full authority for the use of the body after death for transplantation. Yet the parties concerned with donation at the time of death – the donor's family, the physicians and the transplant team – are unaware of this law.

The Act itself creates an opportunity for confusion, stating that if the next of kin have reason to believe consent was subsequently withdrawn, they may contest the deceased's recorded wishes. When this confusion is introduced into the conversation, knowledge of the law becomes irrelevant.

Physicians who work in the Intensive Care Unit are taught to give family oriented care and believe they are required to establish communications and a bond of trust with the grieving family. These physicians told the Panel they felt it was important to work through these serious issues with the family and not to add further stress by attempting to force the family to comply with donation wishes by quoting the Act. When physicians were informed that the Act also provides medical personnel who act in good faith with immunity from lawsuits, the usual response was that protection from lawsuits is not the point. The said that above all, they value the trust they establish with patients and families and they would have to break that trust and "behave like organ-seizing ghouls", which could harm irreparably the public perception of organ donation.

The Panel believes the government should amend the clauses providing for exception in the Act. With changes, this can be a system that can be trusted, that will deliver on people's wishes, and that will improve the dialogue between physicians and families.

The Panel's proposal envisions two steps. First, people's wishes must be known and recorded. Second, but inextricably linked to the first, this information must be available to the care-giving team and family at the time of crisis. This crisis inevitably occurs in an Intensive Care Unit or Emergency Department.

The Panel proposes that certain government forms should ask people their preferences on organ donation. Recognizing that people also have the right not to choose, the forms should provide three options: Yes, No, or Undecided. Since everyone in Ontario has an OHIP card, which must be renewed regularly (once the red and white card is phased out), getting people to choose one of these options upon renewal would – in a few years – result in everyone in Ontario stating their donation wishes.

This information would then be collected and placed in a database. Most critically, however, that database must be made available 24/7 to people in the appropriate setting. The Trillium database already is available to hospitals 24/7. Trillium knows the health care professionals involved in the donation process and has instituted a secure process for confirming their identities. (Security was one of the issues people raised with the Panel.)

Therefore the proposed central database should forward its data regularly to Trillium which then can make it available when needed. The law currently allows this. On average, the Trillium system would have to handle about two requests a day.

To institute this, the government must first clarify the law to make it abundantly clear that a person's consent can only be overridden where there is clear evidence of a subsequent withdrawal of that consent. The clear evidence requirement could be met, for example, by:

- Requiring the withdrawal in writing, or
- Requiring a sworn statement of the person's withdrawal by at least two close relatives.

Therefore, the Panel recommends the government:

- Amend the clause in the Trillium Gift of Life Act allowing consent exemption to require tangible proof of withdrawal.
- Require people to respond to a question about organ donation preference on some government forms, such as the OHIP renewal form.
- Select a central database to record people's donation preferences
- Mandate this database to send its information regularly to the Trillium Gift of Life Network, which will then make it available to families and appropriate health care providers in hospitals when needed.
- Establish an appropriate education program to help everyone understand:
    - What the law is
    - That there is a mechanism to make their wishes known
    - That there is a guarantee their wishes will be respected
    - That this information will be available to family and caregivers at the appropriate time

The Panel believes this will change the nature of the dialogue. If the family doesn't already know the deceased's wishes, they and the caregivers will be able to source the wishes in the database. Other jurisdictions have found that when this occurs the dialogue changes to: How can we insure our loved one's wishes are respected?

6 Costs

In the Panel's consultations, Ontarians universally were concerned about the cost of establishing this process and inevitably referred to the cost of the federal gun registry. The Government of Ontario will no doubt have similar concerns – concerns the Panel shares.

There are various ways to cost effectively achieve the Panel's goals. The Kingston database could be expanded, or a new one could be established as in the U.K. Alternatively, the motor vehicle database could be used as in the U.S. An expert review and analysis should be undertaken to recommend the most economic method of establishing such a database.

OHIP already experiences significant costs with its current database, but was unable to identify these costs for the Panel. As of February 2007, OHIP had recorded the organ donor preferences of slightly more than six million Ontarians. The expert review the Panel is recommending should consider the advantages of continuing and enlarging the OHIP database.

As part of its mandate, the Panel has reviewed costs for establishing databases and registries in other jurisdictions. These costs include those for start-up, implementation, and ongoing maintenance and are reviewed in Appendix 10.

At the present time, volunteer organizations also provide organ donor cards. The proposed system should allow these organizations to transfer their information to the database in advance of the time Ontarians normally would come into contact with one of the government forms requiring a response.

Ontarians should also be able to enter their own preference information online.

These processes also would allow people to be directed to a Trillium website or to indicate that they wanted more information from Trillium.

7 Education

If we want people to understand and believe that their donation wishes will be respected, we must justify their faith by demonstrating exactly how the system will work.

The education program the Panel is recommending will ensure that:

- The public receives the message that the government guarantees their donation wishes will be respected
- The public understands the legal framework and the process to achieve this guarantee
- The public understands that the wishes of others are to be respected and that law and practice also support this
- Physicians and nurses are fully informed about the new reality
- Specific education on donation is provided for those more intimately involved by the nature of their professional activity

The public voiced many concerns to the Panel during our numerous consultations. Many of these concerns were founded on myths and misperceptions of organ transplantation. These beliefs and attitudes form a barrier to those people considering transplantation. A public guarantee that their wishes will be known and respected and a demonstration that this promise is real will go a long way towards alleviating concerns so that people can seriously consider the matter itself.

Therefore, the Panel recommends:

- The Ontario government develop a public education campaign to:
  - Inform Ontarians of the guarantee that their wishes will be respected.
  - Explain to Ontarians how this will be accomplished.

Participants agreed that educating young people is the best way for society to develop an informed attitude about organ donation. There was universal public support for reaching out to young people even though they understood that this education would not be the answer to the present waiting lists in Ontario.

They did, however, identify some immediate benefits of educating young people, noting that children had been very influential in getting their parents to quit smoking or buckle up.

A unique education program in the London, Ontario area demonstrated that education can lead to a real understanding of the issues. This pilot program, known as *One Life…Many Gifts*, has been in operation in some London high schools since 2001. Today, all 38 secondary schools in two London area school boards are involved. Further, a Sudbury School Board has now adopted it in its 10 schools. In all these instances, teacher and student reaction has been overwhelmingly positive. The panel supports a current proposal to enhance and expand this program at a cost of about $400,000, which would be shared by government and the private sector.

Therefore, the Panel recommends:

- *One Life…Many Gifts* be piloted in other English and Francophone school boards.

There are other successful models for reaching out to young people. As part of its anti-smoking campaign the Ministry sponsored – with input from a 16-member youth advisory panel – a very successful web site *stupid.ca*. This educational site employs a mixture of cutting-edge graphics, interactive games, gross humor, and anti-smoking factoids to bluntly inform teens about the dangers of smoking. It drew more than 600,000 unique visitors in its first six months and has won several top Canadian and international awards.

Therefore, the Panel recommends:

- Consideration be given to creating a youth-oriented website and other youth-oriented programs about organ donation.

8 The Role of Religion

Religion plays a central role in many Ontarians' lives, strongly influencing their decisions. The Panel focused on religious affiliations in an effort to determine how important these connections were in terms of donation. We found they are very important. At a time of crisis when a loved one

dies, everyone is in uncharted territory and there are few reference points for guidance. The Panel discovered that even those who do not consider themselves to be very religious will reach back to their faith to make an ethical and moral judgment on donation.

Some individuals expressed a vague belief that their religion required them to be buried "whole". Some knew that their religion permits donation while others rejected the idea, saying: "we don't do that".

The Panel undertook an extensive review of the official attitudes of religious groups in Ontario, (Appendix 11). We found that, officially, all major world religions permit organ donation. Notwithstanding that, the Panel heard from some who said their particular faith leader had spoken against donation either privately or publicly.

The Panel also heard from physicians, nurses and chaplains who have dealt with families when a loved one has died. They have witnessed the importance of religion in the decision making. The Panel notes that the families are unlikely to recognize these physicians, nurses and chaplains for their religious expertise, and, in fact, they may not be of the same faith as the family in distress.

It became clear to the Panel that if this matter is to be clarified it must be clarified by religious leaders themselves. The Panel contacted a variety of religious leaders who indicated an interest in doing so.

The most useful model the Panel found was one developed in the United States. There, the approach has been formalized on a multi-faith, nationwide scale. Religious communities throughout the U.S. observe *A National Donor Sabbath* in the same week every year. An entire program of information is built around these Sabbath days. (Appendix 11)

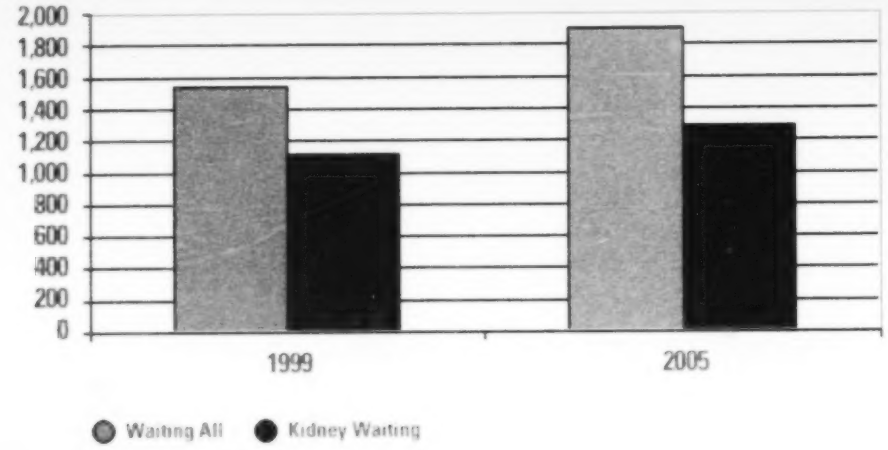
Therefore, the Panel recommends:

- The Government bring together religious leaders to discuss creation of a Donor Sabbath and to engage religious schools in organ donation.

9 Availability of Organs

A complex array of interconnected factors ranging from individual behavior to societal norms, and from medical breakthroughs to demographics, determine how many organs are needed and how many may become available for transplant. Between 1994 and 2004, organ transplantation increased by about 20% in Ontario. In the six-year period from 1999 to 2005, however, the number of Ontarians waiting for organ transplants increased by 25%. (Chart 1)

Chart 1: Number of Patients Waiting for Organ/Kidney Transplant in Ontario,1999 and 2005
(Source: CORR)



There are three sources of organs for transplantation:

- Donation after brain death (DBD)
- Donation after cardiac death (DCD)
- Living donors

This report focuses on the contribution each of these three organ sources can make. Each source has limitations which must be recognized and managed in order to optimize organ availability.

9.1 Availability of Organs after Brain Death

Brain-dead donors potentially can donate their kidneys, lungs, heart, liver, pancreas, small bowel and other tissue components. No other source can provide as many organs.

At the same time, it is important to understand that there is an absolute limit to the number of donors who suffer brain death. Most people do not die of brain death. To be a brain-dead donor, a person must die in hospital and in an Intensive Care Unit (ICU) where all the necessary care can be given to maintain the organs immediately.

Brain death is determined, according to strict medical criteria, by two different physicians who are not associated with the transplantation. Additionally, prior to death, the person must not have any disease process – such a cancer or infection – which would pose a threat to the recipient.

In all, less than 1% of those who die in hospital each year meet the strict criteria for donation after brain death. These people arrive at a hospital emergency department with a catastrophic brain injury.

Over the years, there has been a continuing decline, relative to the population, in the number of people who die of a catastrophic brain injury. About 50% of people who become donors have arrived with a cerebral vascular accident (CVA) – the rupture or clotting of blood vessels to the brain such as that which happens in a stroke or aneurism.

Most of the public discussion about brain-dead donors focuses on those injured in motor-vehicle accidents. And yet, that source provides less than 20% of donors. The remaining 30% come from a wide variety of other brain injuries such as industrial, sports, gunshot, or suicide. (Chart 2)

Chart 2: Distribution of Deceased Donors (%) by Cause of Death, Ontario, 2003 – 2006
(Source: CORR)

CAUSE OF DEATH	2003	2004	2005	2006
Cerebrovascular	53	61	57	44
Trauma from Motor Vehicle	12	13	14	17
Other Trauma	15	8	14	9
Other Unkown	8	10	7	17
Anoxia/Hypoxia	10	6	7	9
Gunshot	1	2	2	2

The reason these sources are declining is apparent when one reviews the state of Canadians' health over the past decades.

First, better medical care and treatment for high blood pressure has resulted in fewer people dying from strokes and vessel rupture. Less salt in the diet and better cholesterol control also means fewer strokes. The result: The number of Ontario deaths from CVA is half what is was 30 years ago and today is about the lowest in the industrialized world.

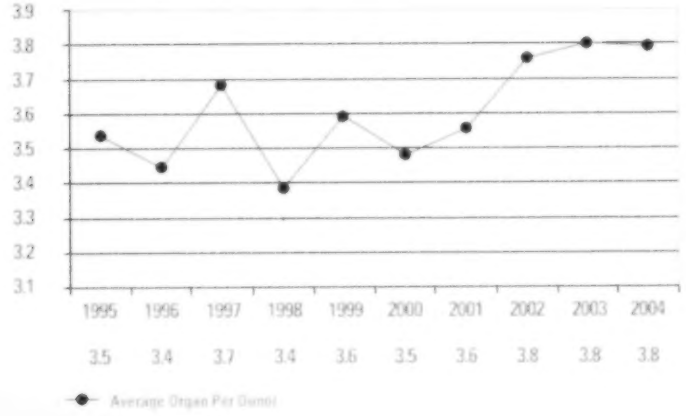
Second, deaths from motor vehicle accidents have also decreased significantly. Seatbelts, airbags, and drinking-and-driving laws all have contributed to the decrease. Helmet laws have resulted in the lowest death rate in the world for those who ride two-wheeled vehicles. Additionally, tremendous advances in highway design and construction have made the roads safer than ever before. Overall, these positive factors have led to decreased death rates. We can expect society will continue to be interested in reducing deaths from motor vehicle accidents.

The fact that transplants have increased only modestly in the past years has been widely seen as a possible system failure. While it is clear there are many improvements to make, the Panel suggests that perhaps any increase should be considered a sign of success given a relative decrease in the sources of organs and the limitations of the present system.

Availability is one thing; efficiency is another. It is clear there is an obligation to use every potential donor to the maximum benefit. It is important to review the evidence which shows great strides have been made in this area.

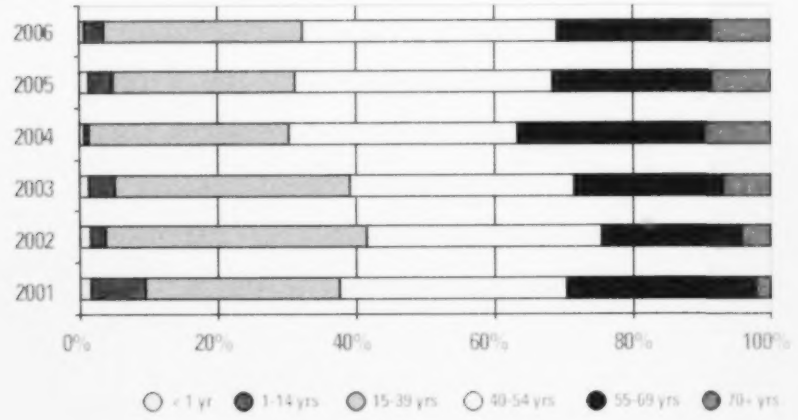
It is difficult to maintain a brain-dead patient in such a state that all the deceased's organs are suitable to retrieve. Ontario reaches the best standards internationally by obtaining on average 3.8 organs from each brain-dead donor. (Chart 3)

Chart 3: Average Number of Organs Used for Transplantation, Canada, 1995-2004 (Source: CIHI)



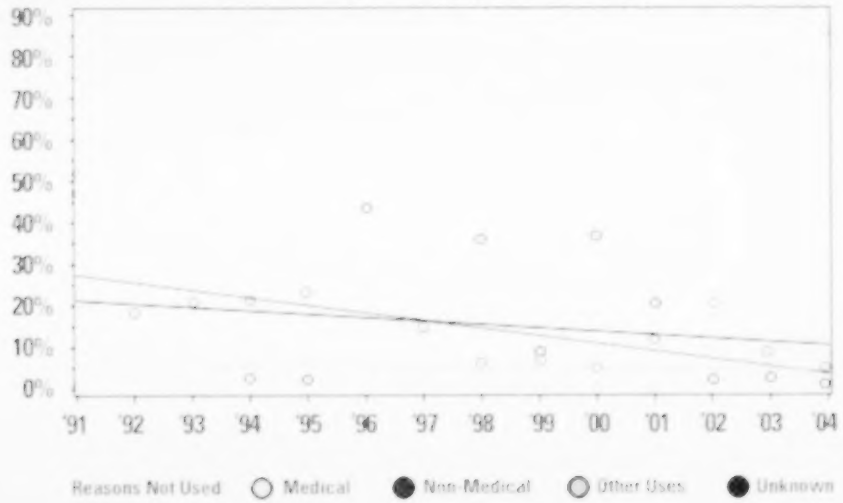
Where it was once thought that older patients could not become donors, donations from those over 70 is now common. In fact, the oldest donor in Ontario was 94. (Chart 4) Despite the fact that older donors have health problems that may impact various organs, Ontario still has been able to maintain its 3.8-organ average.

Chart 4: Distribution of Deceased Donors by Age Groups, Ontario, 1994-2004 (Source: CORR)



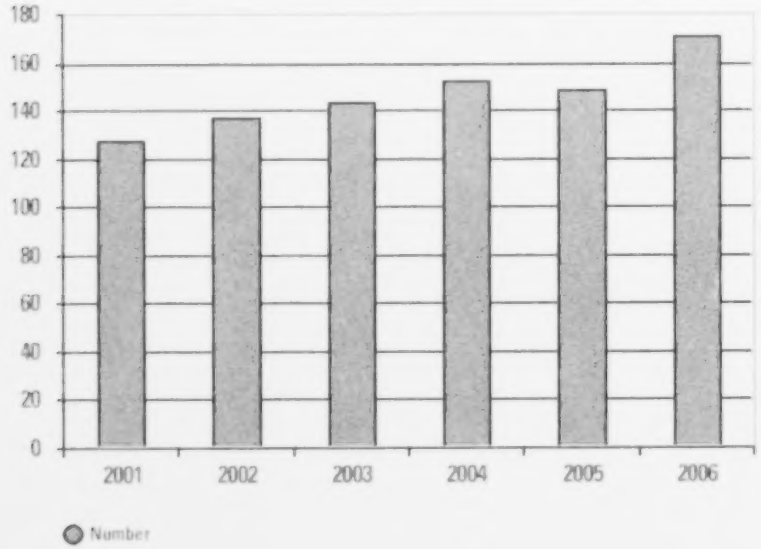
Furthermore, transplantation is a complex system in which many things can – and do – go wrong and organs are wasted. Over time, Ontario has reduced this wastage by carefully reviewing and improving the system to the point that now almost the only source of organ loss is due to a medical problem with the organ itself that could not be detected prior to retrieval. (Chart 5)

Chart 5: Reasons for not transplanting (%), 1991-2004 (Source: CORR)



At the present time, Ontario's organ donation rate is 13.6 per million population – about 170 donors in 2006 (Chart 6). Since the numbers of brain dead patients is limited and once a patient is a donor, efficiency is high, an increase can occur only if more of these patients actually become donors.

Chart 6: Number of Donors in Ontario, 2001-2006 (Source: CORR)



Later in this report the panel will recommend that the National Collaborative standards be adopted. This would establish a goal of 75% conversion of potential donors to actual donors – about a doubling of the present rate in Ontario. This 75% has actually been achieved by some partners in the Collaborative and is a laudable goal, but no one knows if this is actually achievable in Ontario.

This would require significant changes in rates of patient consent. Complex changes in public understanding and in hospital management are required to change these rates of consent and the panel is recommending such changes. With such system changes, 75% represents an appropriate starting goal.

Despite this, and all other things in the organ donation process being equal, the Panel recognizes that it is unlikely that Ontario ever will reach the donation rates of some other jurisdictions, nor would it wish to have that many brain-dead patients.

Some other jurisdictions with higher donation rates have much higher death rates from the most important source – CVA. Some have tremendously higher rates of death from motor vehicles accidents, motorcycle accidents and gunshot wounds. Some have younger demographics with more men working in heavy industry. They have more brain dead patients, so can get more donors, but they are not to be emulated.

The message in the numbers is clear. Donations from the brain dead cannot meet the need even at the Panel's suggested goal. Even to get to this goal will require the serious system reform the Panel recommends in this report. And it will require realistic expectations based on our health facts in Ontario. Failure to do so will ensure a permanent inability to achieve these goals and the resultant assignment of inappropriate blame.

9.2 Newly Developing Sources of Organs for Transplant

Two developments hold great promise for a significant increase in the number of organs available for transplant, most notably kidneys and liver. To be most effective, both will require new approaches. However, both may be accomplished within the present skill set of our health care system, since each is practiced already in Ontario.

They are: Donation after cardiac death and living donation. Donation after cardiac death is just beginning and has a definite limit to its growth. Living donation, although firmly established in a few centers, needs nurturing to grow, but realistically could be expected to dramatically reduce the waiting time for kidney and liver transplant.

9.3 Donation after Cardiac Death (DCD)

Whereas in donation after brain death the heart is still beating and providing circulation to the organs of the body, in donation after cardiac death the organs are taken shortly after the heart stops beating from natural causes. In both cases the fundamental rule adhered to is that the recovery of organs must not be the cause of death.

When the heart stops beating, nutrition and oxygen are no longer being provided to the organs. It is, therefore, necessary for the transplantation to be done quickly. This requires hospitals to establish entirely new protocols, some of which may result in unique stresses to the system.

Donation after cardiac death, however, is neither as new, nor as radical, as it first appears. In Japan, for example, the culture results in virtually all kidney donations being DCD.

Furthermore, we have practiced DCD in Canada in the past. However, over time, Canadian physicians recognized the clear advantage of donation after brain death – that virtually all organs could be preserved and beneficially used – and this became the preferred approach, throwing DCD into disuse.

However, today, due to the continuing severe shortage of organs DCD has been reconsidered and treatment protocols – National Recommendations – have been developed. These were developed by the Canadian Council for Donation and Transplantation and published in the Canadian Medical Association Journal to provide guidance to hospitals and clinicians. About a dozen DCD cases have now been done in Ontario and more than 100 have been done in United States.

Because of DCD's significant utility, the new and demanding nature of these protocols, and because it is a wise approach to introduce this method using teams already experienced in transplant issues.

Therefore, the Panel recommends:

- Every hospital in Ontario that provides donors should institute DCD policies consistent with the National Recommendations.

The number of additional organs DCD would contribute is difficult to ascertain, but estimates are that it could increase the number of donations by up to 25%.

9.4 Living Donors

Living donations occur most commonly for liver and kidney transplantation. Living donations are less common for other organs. Ontario has an excellent track record in liver and kidney transplantation and as many kidneys are transplanted each year from living donors as from deceased donors. This ranks Ontario among the most giving jurisdictions in the world.

The province's sole liver transplant program, based at Toronto General Hospital (TGH), has performed more liver transplants than any other centre in North America. Living liver transplants are very demanding surgically and TGH is internationally renowned for its expertise in this procedure.

In our discussions with the public, living donation was seen as one of the highest expressions of altruism. Everyone recognized the seriousness of the decision of a well person to undergo a major, emotionally wrenching surgical procedure. Most said they would seriously consider doing it

if they had a loved one in need, while fewer – but still a significant number – said they would consider donating even if they didn't know the recipient, and were an "anonymous" donor.

The Panel heard extensively from living donors. None regretted donating and all would do it again in the same circumstance. However, each and every one experienced hardships they had not anticipated when they were making the decision to donate.

These included:

- At least two visits by the donor to the transplant centre before surgery can be performed
- Batteries of tests, some of which are exceedingly specialized, to ensure compatibility with the recipient and that the prospective donor is in good enough health to donate
- The need to take repeated days off work for meetings and tests
- The costs of driving long distances, parking and meals, or multiple flights and hotel stays – all of which can stress any family budget and exceed the capacity of many

The March 2006 edition of the Canadian Medical Association Journal noted that about 24% of living donations currently are lost because of anticipated financial hardship.

At the time of surgery other problems present themselves. In addition to the cost of travel there is the time the donor will be off work.

One nurse described this experience: Her husband had been ill for so long with kidney failure that he had been unable to work for several years. She was the family's sole source of income with kids in school and could not have given a kidney to her husband if her employer, a hospital, had not continued to pay her salary while she was off work – because of the strenuous nature of nursing – for slightly more than two months.

On the other hand, the CEO of a software company who gave a kidney to his daughter was only off work two weeks. As he said, he only had to sit at work so it didn't matter whether he was sitting at home or at the office.

Despite the costs to the living donor, those the Panel met with unanimously felt such donations were good for the recipient and all of society – saving health-care dollars for expensive treatments such as dialysis and restoring the recipients to productive members of the family and society. This was one of two items that everyone we spoke with supported unanimously. They felt living donations should be supported by everyone since we all benefit, but many added that they wanted assurances that any money provided as support would be spent carefully. People were very creative in their suggestions of how to accomplish this and the Panel is using much of their advice.

Ontarians told the Panel job security for living donors was a real issue, comparing it to maternity leave, which society has decided is a benefit and therefore has passed laws to provide a job guarantee upon return to work.

Therefore, the Panel recommends:

- The Ontario Government enact legislation to guarantee job security for any living donor.

When it came to wages, people felt company sickness benefits should continue to pay the donor just as they do when employees are sick and off work. They also felt that those who are self employed or have no insurance plan should be given wage support provided by a government fund as a last resort. Some people expressed concern that such plan might be open to abuse but were comforted by the fact that donation of an organ was a very concrete and verifiable event and that this would make abuse less likely.

All said they believed that reasonable expenses incurred by the donor should be reimbursed. British Columbia has a program which incorporates many of the ideas presented to the Panel, including limiting expenses to certain items and capping them at a reasonable amount. In B.C., lost wages are capped at a modest replacement. The donor applies at the hospital where the recipient is receiving treatment and all expenses must be pre-approved. There are no retroactive payments. This government-funded program has been run with very low overhead by the Kidney Foundation at arm's length from the government. Average cost is $800 per donor within a range of from $50 to $3,500 per donor. There is a cap of $5,500 per donor. This is exactly in line with what people thought an Ontario program should do.

Therefore, the Panel recommends:

- The Ontario government establish a fund to pay reasonable pre-approved expenses and to reimburse donors for lost wages.

Ontarians living in the north who face special challenges were very familiar with the Northern Health Travel Grant program and felt it should be extended to cover living donors.

Therefore, Panel recommends:

- The Northern Health Travel Grant program be extended to living organ donors and potential donors.

9.5 Living Donor Database

In some cases, a living donor is willing to give an organ to a loved one but is prevented from doing so because of immunologic incompatibility. In some of these cases, the transplant team is aware of another donor-recipient pair with the same problem and knows that if the two donors pairs switch recipients – a paired exchange – both transplants can be performed. Some centers attempt to maintain a list detailing the immunologic profile in an attempt to facilitate this pairing.

It is apparent that as the pool of donors increases, it will become easier and easier to find an appropriate recipient. If this information were collected province-wide it would facilitate, for

example, an incompatible pair in Windsor finding another incompatible pair in Cornwall to exchange with – to the benefit of all involved.

In fact, matching on a much larger scale could be facilitated, as we have seen elsewhere, with everyone winning and no one losing. Because Ontario has a population of more than 12 million people, it is possible to say that most could become donors and every recipient could find a match.

Ontarians are willing to become living donors. The more certain people are of success, the more likely they would consider donation. Given the population of Ontario, living donations have the greatest potential to reduce and eliminate the waiting list for kidney and liver transplants.

The information that would be required in such a database is very similar to the information Trillium keeps already in its recipient database. It would require only a change of scale, not development.

Therefore, the Panel recommends:

- A province-wide database of living donors and unmatched recipients be housed within the Trillium Gift of Life Network.

9.6 Other Considerations

The investments in supporting the living donor program will go a long way towards being self supporting. However, we must consider also the patients and their quality of life.

Without a liver transplant, every person in liver failure will endure a poor quality of life until they die. Those with kidney failure can live for years thanks to dialysis. Despite the fact that dialysis has improved over the years and continues to do so, patients on dialysis say they often do not feel well and often feel terrible. Every kidney recipient the Panel spoke to mentioned the tremendous improvement the transplant brought in their well being. Simply put, an organ does a better job than a machine. Happily, an organ is also cheaper.

Life saving dialysis is expensive. The cost depends upon many factors, but ranges from $40,000 to $65,000 a year. A transplant costs about the same in the year it is performed, but each year thereafter the cost drops to about one-fifth the cost of dialysis.

Overall, it costs the health-care system $30,000 to $50,000 a year less to maintain a transplant patient than it does to maintain the same person on dialysis. Ontario now has about 5,000 patients with functioning transplants, saving the system about $200 million each year. With slightly less than 9,000 patients on dialysis, there are hundreds of millions of dollars more to be saved with more donors.

The Panel has recommended investments in the organ donation system, but a balanced consideration of these investments should bear in mind the financial benefits to the province of transplants as demonstrated in this one area alone.

That said, the Panel recognizes that people are not motivated to give an organ because it will save the health-care system money. They give out of a blend of love, affection and altruism. It is, however, in the best interest of those in charge of the system to support that gift on behalf of all Ontarians.

10 In The Hospital

Donor families and professionals inside the hospital focused the Panel's attention on three key areas:

- The experience of donor families
- Hospital-specific issues, and
- The intensive care unit

10.1 The Experience of Donor Families

Many organ donors come from among the healthiest members of our population. Their family is accustomed to that person coming and going until one day that person is in the emergency department or intensive care unit with a sudden catastrophic injury. For any family, this is a time of profound disorientation.

Disbelief, sadness, anger, and numbness among the emotions that sweep over each member of the family. Initially, the family and the medical staff may not be fully aware that these injuries will result in death. This is a time when communication between caregivers and the family is critical. At some point, it will become apparent to someone that this patient could be a potential donor. But the communication of this may be very difficult. Not everyone has the capacity to stand in the presence of a deeply anguished family and raise the subject of donation.

Families fervently hope for the best and sometimes have difficulty accepting the inevitable outcome. As such, they are likely to misread the health status of their loved one. Their relative is on a respirator, and the natural colour of the patient and the regular breathing caused by the machine feed into nature's way of using our emotions to deny reality until it is forced upon us. The Panel heard from family members who were shocked when they were asked about donation, and denied the request because they believed the victim was improving. In hindsight, they understood what had happened, but at the time, their negative reaction was normal.

By creating opportunities to communicate with families, the medical and nursing staff can help them understand the true status of their relative's condition. Many hospitals use chaplains and social workers with great success in the communication process. The Panel believes there is no one way to set up an effective communications team in these situations, but clearly a team effort benefits everyone.

The Panel also witnessed teams who analyze their support and information sharing with families in a constructive and self critical way. We commend them as models. The approach to families and

the support of them is a difficult, but teachable, skill which needs to be introduced as new staff are hired and refreshed continually with experienced staff members.

The deep grief of a loved one's loss is lasting, but families said that knowing that in death their loved one improved and saved the lives of many others at least gave them the ability to focus on some glimmer of good in an otherwise vast darkness. Some said that as time passed this glimmer has grown to become a comfort to their lasting pain. This, of course, makes effective communication with the family even more important. It would be a disservice to a family not to have this opportunity for closure.

Timeliness is an issue if a patient who looks to be recovering – but is already irretrievably brain dead – is kept on life support too long because the family has not understood the true situation. In such cases, at some point the opportunity will pass when the organs may be preserved and retrieved and then even if the family decides to donate, it will be too late.

Therefore the Panel recommends:

- Hospitals consciously select the team that will support families of potential donors. In turn, these teams should be supported with regular, continuing education and case review. Trillium should be engaged to provide consistency and excellence in training.

The Panel heard from groups developed by volunteers to support families and patients involved in the organ-donor process. These are, of course, very local initiatives and some areas are more developed than others. This volunteer effort is worthy of support particularly as it applies to helping one area learn from another.

Therefore the Panel recommends:

- The Ministry of Health and Long-Term Care or the Trillium Gift of Life Network sponsor a conference (or several regional conferences) of volunteer support groups to enhance mutual learning and to examine the opportunity to replicate these local models across the province.

10.2 Hospital-Specific Issues

Just because a donor provides an organ doesn't necessarily mean that a recipient can be found. Poor tissue matches, different physical sizes, and varying immune sensitivities may make it difficult to find a recipient. Since everyone is eager to see every available organ used, adjacent jurisdictions will ask neighbouring hospitals if they have a suitable recipient when the donor hospital has none. As a result, Ontario works with Quebec and neighboring U.S. states to both give and receive donated organs.

Time and distance restrict the jurisdictions Ontario can work with. British Columbia, for example, is just too far away. But with nearer jurisdictions, the Panel was pleased to learn just how efficiently

organ transfer can work and how frequently it is done. We encourage Ontario and its neighbours to continue this process as much as possible to insure the efficient use of organs.

There is one caveat. The Panel learned that when a Canadian hospital accepts an American organ it must pay the reasonable costs the donor jurisdiction has incurred for retrieval. In the American states, this ranges from US$20,000 to US$60,000 depending on the organ. Last year, two Ontario hospitals paid a total of more than $400,000 each in these reasonable costs. But it is worth noting that such costs are not included in the budget they receive from the Ministry of Health and Long-Term Care. This additional unfunded cost puts tremendous pressure on the rest of the hospital's budget.

More surprising, when a Canadian hospital sends an organ to the United States there is no charge. The organ is provided free. The Panel finds this to be a shocking state of affairs. Our hospitals have real costs, too. We are delighted that an American citizen can benefit when a Canadian organ cannot be used here, but there should be a charge for the Canadian organ. At present, Ontario law prevents organs from being bought or sold. While this may be the case, it is nonsense to suggest that asking for reimbursement of reasonable costs is the same as selling an organ. If this were true, the Ministry would be guilty of buying organs when it pays the costs of Ontario hospitals. Furthermore, under this interpretation Ontario hospitals would be guilty of buying organs from the U.S.

Reasonable cost must be reimbursed. On balance, Ontario citizens are funding the American health-care system. This should stop and it should stop now.

Therefore, the Panel recommends:

- The Ministry of Health and Long-Term Care provide Trillium with a fund to reimburse reasonable costs to American hospitals.
- Trillium be allowed to collect reasonable costs of Canadian organs from American hospitals and that these costs should mirror American costs.

Transplant hospitals also face other challenges. Once a patient is accepted into the transplant program, he or she will have to live close to the facility and any illness – even one unrelated to their organ failure – will be much more complicated and will require treatment from the transplant hospital. This will mean frequent visits sometimes two or three times a week. After transplant, these recipients will be patients of a transplant hospital for life.

The complexities of hospital funding are beyond the scope of this Panel, but we feel that the Ontario government should undertake a careful review to make ensure proper funding.

10.3 The Intensivist Dilemma

At present, neurosurgical ICU beds are at a premium. Frequently, every bed in the province is filled and many patients must be sent out of province. A neurosurgeon might have two patients

with brain injury but only one neurosurgical ICU bed. In this example, the one patient has irreparable brain injury and either is, or will shortly become, brain dead and be suitable to donate organs. The other patient in the same emergency suite may have brain injury requiring a neurosurgical ICU, but with the promise of recovery.

In this circumstance, the neurosurgeon is duty bound to admit the patient who may recover to the ICU. Inevitably, this means no organs will become available from the other patient.

Although it was first posed to the Panel in the neurosurgical context, it became clear this dilemma is faced by intensivists as well, who may be forced to set the needs of a patient with septic shock – a lethal but treatable condition – above those of a donor, and again forego acquiring potential organs.

The Panel is aware that a Critical Care Strategy for Ontario is well under way. We are satisfied that those leading the endeavour fully understand this dilemma. However, donation has not yet been included in Critical Care Strategy planning.

Therefore, the Panel recommends:

- The Critical Care Strategy group should include organ donation in the planning and consideration of resources needed for an increase of donors to more than 300 per year and widespread use of Donation after Cardiac Death.
- The Critical Care Strategy group should work with Trillium to develop processes and protocols.

The Critical Care Strategy group has said they are willing to undertake such initiatives.

We do not know how frequently this dilemma occurs since there has been no attempt to measure it. Given the impact this can have upon donation, Trillium should convene a process involving intensivists and the Critical Care Strategy group to conduct a pilot study to assess the magnitude.

10.4 The Intensivist Role

The role of the transplant physician is well recognized. However, the role of the intensivists is unknown to the public. Without the intensivist there would be no donation, and the transplant surgeon and physician would have nothing to do. The intensivist receives these catastrophic injuries, makes life and death decisions – sometimes by the minute – and attempts to communicate all this to a family in trauma.

Furthermore, the maintenance of a donor after declaration of brain death is extremely demanding and in many ways unlike the maintenance of other patients. Success comes with practice and extreme vigilance. The Panel considers the intensivists and their teams to be the unsung heroes of transplantation.

These people approach this difficult task with care and dedication in spite of:

- The enormous amount of additional work – much of it unpaid – in maintaining a donor
- The requirement that two physicians determine brain death – an exacting and time consuming activity that, for some, is not covered in the fee schedule
- The significant increase in unpaid time required – under the recommendations of this Panel – to interact with donor families – over and above that spent with other families in the difficult ICU environment

An investigation of the fee schedule is beyond the capacity of this Panel but we feel these services are valuable and should be paid accordingly. It is best not to discourage our heroes lest their enthusiasm wear thin.

Therefore, the Panel recommends:

- A special study of intensivist compensation for donor management be commissioned, the results of which should advise the Ministry of Health and Long-Term Care, and the Ontario Medical Association, in the future determination of fees.

11 A New and Clear Mandate

The ICU is the only source of organs from deceased donors. The ICU is an integral part of the hospital environment and yet two general sets of issues occur in the hospital which determines the activity in the ICU and the ability of transplant teams to have organs available. Although these issues are longstanding, a recent management innovation holds the promise of a solution.

11.1 Interdependence

Transplantation activity is asymmetric and necessarily variable across the province. Some hospitals only have patients who can donate. Some others can retrieve and implant organs. Still others can implant some organs but not others. And finally, some hospitals do not have the capacity to do either.

Thus, there are some areas in Ontario that are entirely dependant on other areas to do all the transplants for their patients. At the same time, that same area may contribute organs which are transplanted elsewhere into patients from other areas. Even a tertiary-care hospital will retrieve organs and send them to another centre, either because they don't implant that type of organ or there is no suitable local recipient.

This illustrates the intense interdependence of each area of Ontario. This interdependence results in a mutual set of obligations and responsibilities. These obligations and responsibilities have been only partly acknowledged and they remain uncodified.

11.2 Focus

Hospitals are places of intense pressure and fine balance. The pressure comes from the needs of the community which presents a diverse set of problems – each as pressing as the last – at the hospital door. Hospitals struggle to achieve a balance in meeting one need while not short changing another. Of course, faced with such a spectrum of challenges, hospitals will choose to excel in one area and decide to de-emphasize another.

The Panel found that some hospitals do not focus on the donation process. As a result, one part of the health-care system does not support the others. The Panel wishes to caution that these hospital decisions should not result in censure since no societal mandate has been given them to indicate they should include donation in their focus. The Panel believes such a message is warranted.

11.3 A New Method

Under recent provincial legislation, Ontario has been divided into 14 Local Health Integration Networks (LHINs). The diverse resources and interdependence of hospitals now extends to LHINs. An individual LHIN often will have an organ provided to one of its patients from another LHIN.

Under the new legislation, the LHINs enter into an accountability agreement with the Ministry of Health and Long-Term Care. These agreements specify the expectations for health care in that area. The Panel recommends the Minister indicate strong interest in donation in these agreements and that these agreements be consistent across all LHINs. These agreements should enunciate several principles:

- That each LHIN should work within its boundaries to facilitate organ donation and transplantation consistent with its capacities
- That each LHIN should develop cooperative relationships with other LHINs at an administrative and service level to facilitate transplantation
- That LHINs should facilitate cooperative endeavors with the Trillium Gift of Life Network to enhance organ donation processes within their LHIN
- That each LHIN provide an appropriate data stream – consistent with that of other LHINs – to the Trillium Gift of Life Network

Therefore, the Panel recommends:

- The Ministry of Health and Long-Term Care include organ donation in the accountability agreements with LHINs beginning with the 2007-08 fiscal year.

The Panel chose this year so that no time will be lost. We did so with the full knowledge that these processes cannot be in place for the 2007-08 fiscal year but with the belief that by starting this year, real processes can be in place by next year.

11.4 LHINs and Hospitals

LHINs, in turn, strike accountability agreements with their hospitals. These agreements can give practical reality to the donation requirements in the LHINs' agreements with the Minister.

It is important the agreements between LHINs and hospitals are consistent across the province. If each LHIN attempts to develop these on their own, they will face needless duplication of expertise. Indeed, there is a risk of insufficient expertise to do the job. The Panel believes the Trillium Gift of Life Network should be consulted by the LHINs to ensure consistent policies and agreements across the province.

Trillium already possesses much of the knowledge required and is in the process of acquiring the remaining knowledge it needs. Appropriate use of the Trillium Gift of Life Network will minimize the actual burden on LHINs and hospitals in developing these policies.

No policy should be implemented without generating a resultant data stream so that we can measure the effectiveness of the policy and efficiencies in policy direction, and institute continuous improvement. Hospitals and the Trillium Gift of Life Network should begin to develop realistic and practical measurement parameters. Trillium should provide regular feedback to hospitals and LHINs.

Several practical matters should be addressed in the initial Accountability Agreements:

- First. With significant Canadian input, the Organ Donation and Transplantation Breakthrough Collaborative in the United States has developed an integrated set of policies and continuous improvement steps for hospitals. These hospitals now have a track record of doubling the number of donors compared with jurisdictions like Ontario. In Ontario, the U.S. Best Practice of a 75% conversion rate from potential to actual donors would result in a doubling of the number of donors here. These Best Practice Steps from the Collaborative should be instituted in Ontario.
- Second, the government should institute a process to support ICU physicians in the difficult area of donor maintenance. Educational opportunities, availability of second physician, and the nature of the problems encountered should become a data stream to the Trillium Gift of Life Network.
- Third, a basic curriculum of donor maintenance should be established and delivered to help highly skilled ICU nurses integrate their activities with those of the coordinator to ensure maximum effectiveness. The Trillium Gift of Life Network, which is involved with the Organ Donation and Transplantation Breakthrough Collaborative in the United States, should provide the centre for these educational opportunities.
- Fourth, a data stream should be developed from the health record which encompasses more than Required Reporting, potential, and actual donors. This data should become a matter of study within each LHIN and should be shared widely within the LHIN. Furthermore, within the year, LHINs should begin to share their data with each other and should collectively investigate with Trillium how the data stream can be made better and

used for practice improvement. With time, much of this data should become public. This will close the circle of interdependency and mutual responsibility.

Therefore, the Panel recommends:

- Each LHIN strike an accountability agreement with its hospitals that reflects the provincial priorities.
- LHINs should cooperate with and use the Trillium Gift of Life Network as:
  - Their common source of knowledge
  - Their common database on transplant matters
  - The facilitator of education

12 Trillium Gift of Life Network

The Trillium Gift of Life Network has figured prominently in many of the Panel's recommendations in this report. At the beginning of its study, the Panel took a deliberately neutral attitude towards the Trillium Gift of Life Network. As the Panel began to understand the changes required and the attributes of an improved system, it became apparent that Trillium understood and was undertaking efforts in almost all of these areas. It further became apparent that the Trillium Gift of Life Network's efforts were hampered by the system it found itself inheriting and given the illusions and the anomalies, it struggled to make the best of it.

During the Panel's consultations, it became abundantly clear there was confusion about the Trillium Gift of Life Network's name. People were much more familiar with the Ontario Trillium Foundation, an agency that funds arts and community groups, and in some areas of the province people confused it with the Trillium Health Centre in Mississauga. Participants found that the name gave them no clue as to the purpose of the organization. The Panel wonders how an organization can thrive with a name that confuses seemingly all of its target audience. The Panel also wonders how, when it is not associated with donation and transplant, Trillium can establish a leadership role.

Therefore, the Panel recommends:

- Trillium Gift of Life Network be allowed to change its name to something less likely to lead to misunderstanding and more in accord with its mandate.

The Panel's mandate did not include reviewing the budgetary expenditures of the Trillium Gift of Life Network. The Panel is, however, aware that the significant increase in responsibility and mandate recommended by this report will require the Trillium Gift of Life Network be given additional resources. The Panel cannot measure the magnitude required and does not know if there are internal efficiencies to be gained while achieving this new mandate. The government should conduct an immediate review of this matter to ensure timely implementation of the Panel's recommendations.

Therefore, the Panel recommends:

- The government allocate sufficient resources to the Trillium Gift of Life Network for it to carry out its new mandate.

13 National Issues

The Panel's mandate did not include exploring national issues on transplantation. However, in the course of its work and in reviewing the systems in the United Kingdom and the United States for guidance, the Panel discovered great benefit in national endeavors. It also reviewed national policy statements and guidelines and found these to be of great benefit. The Canadian Council for Donation and Transplantation, based in Edmonton, helped the Panel understand many key issues.

It's clear that some issues are best addressed on the broadest scale possible. For example, the argument made in this report that organ trades across the province would be more likely to guarantee appropriate matches, is even more compelling if extended to the entire population of Canada.

Therefore, the Panel recommends:

- That wherever and whenever practical and beneficial, Ontario cooperate with other provinces to the fullest extent in developing approaches and systems to support organ donation.

Given the history of developing national initiatives, Ontario should not wait to introduce the recommendations in this report. However, as it does so, it should demonstrate a willingness to cooperate with any jurisdiction on any donation matter, and develop systems with an eye to allowing them to mesh or integrate with other systems in other jurisdictions in the future.

14 Conclusion

The Citizens Panel on Increasing Organ Donations found its discussion with citizens of this province to be most gratifying. Organ donation is a serious subject and people showed a genuine willingness to discuss it in a constructive way. People recognized the importance of organ donation and overwhelmingly supported it as being part of our health-care system. Every person in Ontario comes from his or her own unique background and every person the Panel spoke with attempted to grapple with these issues on a principled and ethical basis founded in their experience and beliefs. As expected, people held different views, but their willingness to hear and understand other points of view cemented the Panel's opinion of the wisdom of the people of Ontario.

People were unanimous that they wanted to have their wishes respected upon their death and yet the Panel discovered that people wrongly believed that guarantees of this already were in place.

The Panel also discovered people held false expectations of the organ donation system and had been given false promises by those promising a single, quick fix.

Instead, they discovered a health-care system with a disparity of direction on organ donation and a lack of collaboration and the presence of non-systemic thinking by providers.

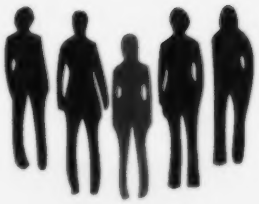
The Panel's proposals aim towards developing a transparent system where the promise that people's wishes will be respected can be kept. The Required Response mechanism would allow people to register their wishes. A real and functional database, available 24/7, will make certain that those wishes are known at the proper time. An education campaign to make people aware of this new system will increase people's confidence in the organ donation and health-care system by guaranteeing their wishes are respected.

The nature of the dialogue at the time of crisis also will change. At the time of consideration, the ICU team will be able to inform the family what the wishes of the individual were by accessing the database. In the event that the family is unaware of those wishes, the team will be able to bring this knowledge to the discussion. Everyone will understand that it is their duty and obligation to respect the wishes of the newly deceased, and the actions of the team will simply give reality to those wishes.

A clear statement by the Ontario government of the importance of the organ donation system and giving effect to that statement through in-system development, as outlined by the Panel, holds the promise of doubling the number of donors annually from brain-dead patients, of increasing donation after cardiac death by up to 25%, and of expanding the living donor program. Together, all these will make a massive contribution to decreasing the waiting list, while at the same time saving the health-care system hundreds of millions of dollars.

The Panel believes Ontario must carefully look after all of the parties involved in the system in new and creative ways. The people we consulted were unanimous in believing that living donors should be supported. The Panel agrees, and it also found it important that key partners – such as the hospitals and those in the ICUs – receive proper incentives, and that any disincentives be eliminated.

The Panel believes we can do better. It believes the Government of Ontario is committed to doing better. And it believes the people of Ontario want us to do better and will support our efforts.



THE CITIZENS PANEL ON INCREASING ORGAN DONATION

Seeking views and opinions on increasing organ donation in Ontario

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Appendix 1: List of Recommendations

Following extensive consultations with the people of Ontario, discussions with experts in the field and a review of previous reports on organ donation, the Citizens Panel on Increasing Organ Donations recommends that:

The Law

- The clause in Trillium Gift of Life Act allowing exemption to consent be amended to require tangible proof of withdrawal. (pg. 5)
- Some government forms, such as the OHIP renewal, should require a response to a question about organ donor preference. (pg. 5)
- A central database be selected to record people's preferences. (pg. 5)
- This information should be regularly sent to Trillium, which will make it available to families and appropriate health care providers in hospitals at the appropriate time. (pg. 5)

Education

- A public education campaign be run telling members of the public that their wishes are guaranteed to be respected and informing them of how this will be done. (pg. 7)
- The One Life. Many Gifts youth-education program be piloted in other school boards including Francophone boards. (pg. 7)
- Consideration be given to creating a youth-oriented website and other youth-oriented programs about organ donation. (pg. 7)

The Role of Religion

- The Ontario government bring together a committee or conference of religious leaders to consider engaging religious schools in organ donation and implementing a program which sees religious communities throughout the country observe a National Donor Sabbath in the same week every year. (pg. 8)

Donation after Cardiac Death (DCD)

- Every hospital in Ontario that provides donors should institute DCD policies consistent with the National Recommendations. (pg. 14)

Living Donors

- The Ontario Government enact legislation to ensure living donors are guaranteed job security. (pg. 16)
- A fund be established to pay for reasonable pre-approved expenses and lost wages. (pg. 16)

- The Northern Health Travel Grant program be extended to living organ donors and potential donors. (pg. 16)

Living Donor Database

- A province-wide data base of living donors and unmatched recipients be housed at the Trillium Gift of Life Network. (pg. 17)

In The Hospital

The Experience of Donor Families

- Hospitals consciously select the team which will support families of potential donors in the time of crisis. These teams should themselves be supported with continuing education and case review. Trillium should be engaged to provide consistency and excellence in training. (pg. 19)
- A conference – or several regional conferences – of volunteer support groups should be held to enhance mutual learning and to examine duplicating models across the province. (pg. 19)

Hospital-Specific Issues

- Trillium should receive a fund from the Ministry of Health and Long-Term Care to reimburse reasonable costs to American hospitals for the purchase of U.S. organs. (pg. 20)
- Trillium should be allowed to collect reasonable costs from American hospitals for Canadian organs. These costs should mirror American costs. (pg. 20)

Critical Care

- Ontario's Critical Care Strategy should include organ donation in the planning and consideration of resources needed for an increase of donors to more than 300 per year and widespread use of Donation after Cardio-circulatory Death (DCD). (pg. 21)
- The Critical Care Strategy group should work with the Trillium Gift of Life Network to develop processes and protocols. (pg. 21)

The Intensivists' Role

- A special study of intensivists' compensation for donor management be commissioned and the results used to advise the Ministry of Health and Long Term Care, and the Ontario Medical Association in future determination of fees. (pg. 22)

A New Method – Local Health Integration Networks (LHINs)

- The Ministry of Health and Long-Term Care include organ donation in its accountability agreements with the LHINs, beginning with the 2007-08 fiscal year. (pg. 23)

LHINs and Hospitals

- Each LHIN should strike an accountability agreement with its hospitals that reflect the provincial priorities for organ donation. (pg. 25)
- LHINs cooperate with and use the Trillium Gift of Life Network for education and as their common source of knowledge and a common database on transplant matters. (pg. 25)

Trillium Gift of Life Network

- Trillium be allowed to change its name to something less likely to lead to misunderstanding and in accord with its mandate. (pg. 25)
- Sufficient resources be allocated to Trillium to carry out its new mandate under the Panel's recommendations. (pg. 26)

National Issues

- Whenever practical and beneficial, Ontario co-operate with other provinces to the fullest extent in developing approaches and systems to support organ donation. (pg. 26)

Appendix 2: Glossary

Accountability
The measurement and reporting of outcomes to demonstrate that donation and transplantation processes are fair and transparent.

Anonymous donation
Donation from living donors who are not related to or known by the recipient.

Attached
Members of the public who have a personal connection to organ donation and transplantation, whether they know someone who is affected or they themselves are affected. Attached includes those working in the field of hospital services and organ and tissue donation.

Brain Death
The "the irreversible loss of capacity for consciousness combined with the irreversible loss of all brainstem functions including the capacity to breathe". (Canada - Canadian Neurocritical Care Guidelines)

CCDT
Canadian Council for Donation and Transplantation

Cerebrovascular Accident (CVA)
Also known as a stroke, occurring when there is an occlusion of an arterial vessel going to the brain or when there is bleeding into the brain. (Source: UNOS)

CIHI
Canadian Institute of Health Information

CORR
Canadian Organ Replacement Registry – a national information system that records, analyzes, and reports the level of activity and outcomes of vital organ transplantation and renal dialysis activities. CORR is funded by the federal and provincial ministries of health through the Canadian Institute for Health Information (CIHI), which manages CORR.

Critical Care Strategy
Implemented by the MOHLTC, the Critical Care Strategy is the result of an on-going collaboration between critical-care health-care providers, hospital administrators, Ministry officials and others. It was designed to improve access, quality and system integration through an innovative strategy.

Donation after Brain Death (DBD)
DBD occurs when the death of the brain is so complete that it is no longer able to control or support bodily functions.

Donation after Cardiac Death (DCD)
DCD may occur with a patient who hasn't necessarily been classified as brain-dead, but whose heart has stopped as a result of:

- cardiac arrest in a person already "brain-dead,"
- unsuccessful resuscitation of a person in cardiac arrest and cardiac arrest following withdrawal of treatment in the ICU.

DCD from the last category is known as "controlled" DCD, because methods to preserve organ viability are initiated before the donor's death, and timing the death (withdrawal of life-sustaining treatment) can be controlled around organizational factors such as operating room and surgical team availability.

Living Donor transplantation
Surgically removing a portion of a donor's healthy liver or a complete kidney for transplantation into a recipient. A family member, usually a parent, sibling or adult child, or someone emotionally close to the recipient, such as a spouse, may volunteer to donate a portion of their healthy liver. This procedure is made possible by the fact that there are two kidneys and only one is needed and the unique ability of the liver to regenerate. After transplantation, the partial livers of both the donor and recipient will grow and remodel to form complete organs.

Neurological
Having to do with the brain and/or other parts of the central nervous system.

Non-related donation
Living donors such as spouses, in-law relatives, close friends and co-workers.

Paired exchange donation
A program in which two separate but willing donors – both of whom are unable to donate to their intended recipients due to blood group (ABO) incompatibility – are matched with the other's recipient. Each recipient thus receives a compatible kidney.

Potential Donor
Someone who has died and has consented to donation, or someone who is alive and has been approved for donation. In these cases, organs and/or tissues may be recovered.

Presumed Consent
The system by which consent to donate is presumed unless a person has expressly indicated otherwise during his/her lifetime; also known as the opting-out system.

Recovery
Surgically removing organs and tissues intended for transplantation.

Related donation
Donations from living brothers and sisters, parents, children 18 years of age and older and other blood relatives, including aunts, uncles, cousins, half-siblings, nieces and nephews.

Routine Notification and Request (RNR)
Requires that a designated facility notify the Trillium Gift of Life Network as soon as possible when a patient at the facility has died or a physician is of the opinion that the death of the patient is imminent.

Stroke
A sudden loss of consciousness, sensation, and voluntary motion caused by rupture or obstruction of an artery of the brain.

Trillium Gift of Life Network Act
Drafted by the Ontario government in 1999, the Act established the Trillium Gift of Life Network and set its mandates as the organization, promotion, education and coordination of organ donation and transplant services in the province.

Unattached
Referring to members of the public who have no personal connection to organ donation and transplantation. They may also have little or no awareness, understanding, or information about the processes surrounding donation and transplantation.

Appendix 3: The Citizens Panel on Increasing Organ Donations Members

Dr. Ted Boadway – Panel Chair
Dr. Ted Boadway is a medical doctor who spent the first 13 years of his professional career as a family physician and the next 23 years as executive director of the health policy department with the Ontario Medical Association (OMA). Throughout his career, Dr. Boadway has been actively involved in medical politics at the local, regional, provincial, and national levels. In 2003, Dr. Boadway received the Queen's Golden Jubilee Medal in recognition of his published and legislative work in tobacco control. He continues his work in health policy and in health environmental policy through his consulting work with the OMA, the Ontario government and other clients.

Dr. Boadway was a member of the steering committee and then a founding member of the board of Multiple Organ Retrieval Exchange Program (MORE) for the province of Ontario, the predecessor of The Trillium Gift of Life Network. He served as chairman of the board of MORE for three years.

Alvin Curling
Alvin F. Curling was appointed as Ambassador Extraordinary and Plenipotentiary of Canada to the Dominican Republic on August 19, 2005. Prior to this appointment, he was the Member of Provincial Parliament from 1985 to 2003, when he was also elected Speaker of the Legislative Assembly of Ontario. The Honourable Alvin F. Curling has served on numerous advisory boards and committees including as Chair of the Advisory Board to the Caribana Cultural Committee, Member of the Board of Directors of the World Hunger Project, President of World Literacy of Canada, and Member of the Advisory Board to the Chinese Cultural Centre. The Government of Jamaica has honoured him with the Order of Distinction, in the rank of Commander, and most recently, the University of Technology in Jamaica awarded him an Honorary Doctorate Degree, Doctor of Letters.

Peter Desbarats
Peter Desbarats was Dean of the Graduate School of Journalism at The University of Western Ontario from 1981 to 1997. He currently teaches in Western's journalism program conducting a graduate course in Media and Politics. He has worked as a print and television journalist for 30 years in Montreal, London (UK), Winnipeg, Toronto and Ottawa. His most recent media positions were as national affairs columnist for the Toronto Star and Ottawa bureau chief and co-anchor for Global TV. He is the author of 12 books, several plays and numerous academic and popular articles. Peter Desbarats is a member of the advisory board of the Canadian Journalism Foundation, a director of the Canadian Civil Liberties Association and an advisor to the U.S. Society of Environmental Journalists. In addition to lecturing to international audiences and being cited in the media as an authority on Canadian journalism, he has also served in 1995-96 as one of three Commissioners on a federal inquiry (Somalia). In 1991 he was a member of the Ontario Task Force on Cardiovascular Services.

Rev. Brent Hawkes
Rev. Brent Hawkes has been the Senior Pastor at the Metropolitan Community Church of Toronto for more than 29 years and has been at the forefront of the ministry to the gay and lesbian community in Toronto. He has played a significant role in promoting the inclusion of sexual orientation in the Ontario Human Rights Code and the Canadian Human Rights Act. He has served as co-chair for the Campaign for Equal Families, member of the advisory committee of PrideVision TV, and on the Board of Directors of "EGALE" (Equality for Gays and Lesbians Everywhere). Hawkes has been honoured with the City of Toronto Award of Merit along with awards from the United Nations Toronto Association, and the Universal Fellowship of Metropolitan Community Churches.

Gisèle Lalonde
Gisèle Lalonde has many accomplishments throughout her twenty year career as an educator and most recently in the field of politics. In addition to sitting as board chair for the Ottawa Roman Catholic Separate School Board, she held several positions and appointments in the education arena, most specifically related to francophone matters. She also served on the boards of directors of the Royal Ottawa Hospital, Montfort Hospital and Montfort Hospital Foundation. Her political career took flight when she was elected mayor of Vanier, Ontario in 1985 and later sat on the advisory board to the Minister of Municipal Affairs on the professional development of elected officials and municipal managers. Lalonde has been honoured with numerous distinctions and awards including, the Order of Canada in 2004 along with Honorary Doctorate Degree from Laurentian University and St-Paul University.

Senator Joan B. Neiman (retired)
Joan Neiman was born in Winnipeg, Manitoba, and obtained her B.A. from Mount Allison University. She served in the Women's Royal Canadian Naval Service 1942-1946, retiring as lieutenant commander. She was called to the Bar of Upper Canada and practiced law in Ontario 30 years. Neiman served on the Boards of the Elizabeth Fry Society, National Council of Women, Canadian Corps of Commissionaires Ottawa and Admirals' War Medal. She was appointed to the Senate in 1972 where she sat on many standing and special committees and was chair of the Legal & Constitutional Affairs Committee for eight years. She chaired Human Rights Committee of the Interparliamentary Union, the parliamentary equivalent of the United Nations, for eight years. She is a member of an End of Life Project initiated by the Health Law Institute of Dalhousie University and of the Ethics Committee of Orillia Soldiers' Memorial Hospital.

Appendix 4: Terms of Reference

Purpose

The Minister of Health and Long-Term Care has established The Citizens Panel on Increasing Organ Donation comprised of eminent Ontario citizens who will meet with Ontarians to gather their views and opinions on improving organ donation in the province of Ontario.

Through approximately 35-40 public consultations in communities across Ontario and with Local Health Integration Network engagement, The Citizens Panel will gather public opinion on the most appropriate ways that the government can increase organ donation using legislative or other means.

Issues to be discussed will include but not be limited to the following:

- Public views on the matters raised by recent private members' bills introduced in the Ontario Legislature
- Strategies and opportunities to predispose the Ontario public towards organ donation
- Ways in which government can show support and encouragement for living donation
- Other issues related to organ donation as deemed relevant by the Citizens Panel

Scope

In reaching its conclusions, The Citizens Panel should review:

- All relevant aspects of the organ donation process
- Methods of expressing donation preferences and giving consent for organ donation
- Current initiatives of the Trillium Gift of Life Network to increase organ donation
- Best practices in organ donation from other jurisdictions
- Past recommendations for increasing donation

The Citizens Panel's work will exclude:

- All aspects related to tissue donation (bone, skin, eyes, heart valves)
- All activities related to medical procedures re: organ transplantation

Key Deliverables

- A summary of Ontarians' views and opinions related to expressing their organ donation preferences and recording their consent
- A synthesis of the major obstacles to donation choice including public views, beliefs, assumptions and awareness, which may serve as barriers to organ donation
- A synthesis of why some Ontarians do not support organ donation, and why some families do not consent to organ donation
    - Identification of opportunities for greater support for organ donation among Ontario's diverse socio-cultural constituencies
    - Potential initiatives to increase organ donation that are compatible with public sentiment
    - Recommendations of additional strategies which could increase organ donation

- The Citizens Panel on Increasing Organ Donation's report will be instructive to TGLN in providing the Minister with comprehensive advice to increase organ donation in the province.

Context

The issue of organ donation has received much public attention over the last several months. Three private members' bills were introduced in the Legislature during this time, each one proposing different strategies to increase the availability of organs to help Ontarians with end-stage organ failure.

Demand for organ transplantation is increasing due to technological and pharmacological advances, the size and aging population and increasing incidence of end stage organ disease. Organ donation in Ontario and in Canada has not kept pace with the need for organs. For the period 1994-2004, demand measured by wait lists for organ transplants increased by 100%. Organ transplantation increased by only 17% during the same period. While recent years (2004/05 and 2005/06) have seen increases in deceased donation of 14% and 19%, respectively, even greater increases in donation rates will be necessary to meet demand. Currently, 1,757 Ontarians are waiting for organ transplantation.

With the January 9, 2006 proclamation of Part II.1 of the Trillium Gift of Life Network Act, the government implemented Routine Notification and Request requiring hospitals to report all deaths to the Trillium Gift of Life Network. Early results suggest that this has been a successful strategy for increasing donation, and plans are underway to broaden the scope of the requirement.

The ministry recently directed TGLN to provide comprehensive advice and recommendations concerning registering and recording Ontarians' organ donation preferences and to build a system that advances a plan to dramatically increase organ donation in the province. TGLN will receive advice from The Citizens Panel before making final recommendations to the Ministry.

The Organ Donation Breakthrough Collaborative (ODBC) was launched in 2003 in the United States bringing together government, key national leaders and practitioners from transplantation and hospital communities to save and enhance lives by spreading known "best practices" to the largest hospitals in the United States to achieve organ donation rates of 75% or higher. TGLN joined the ODBC in 2004 and has adopted a number of these best practices that have yielded unprecedented record breaking increases in the United States. TGLN is actively supporting implementation of these best practices in Ontario hospitals to improve donation performance.

The Citizens Panel Membership

The Minister will appoint 6 eminent Ontario citizens to The Citizens Panel on Increasing Organ Donation.

The Citizens Panel Support

The appointment of secretariat staff including the Project Lead and Clinical Advisor will be made by the Ministry.

Methodology

Orienting the Task Force

- A literature review will be completed by the Secretariat in collaboration with TGLN in preparation for The Citizens Panel and will include:
  - ethical issues concerning organ donation across Canada and around the world
  - views and positions of various religious, social and ethno-cultural groups
  - role of the federal and provincial governments and related Advisory Bodies
- TGLN will provide background information about Ontario's organ donation process, relationships, and models of delivery, structures, practices, trends, data and statistics, and other details as requested by The Citizens Panel.

Conducting Public Consultation

- The Citizens Panel will host approximately 35-40 meetings in public places across Ontario in October/November/December 2006.
- The Citizens Panel members will need to divide their time in order to meet the ambitious consultation schedule
- The Citizens Panel members will suggest additional avenues for soliciting public views such as an 800 number, remote teleconferencing, letters and e-mail, web forms and electronic newsletters.

Timetable and Milestones

Milestones	Oct	Nov	Dec	Jan	Feb
Hire Strategic Lead and Conduct Literature Review					
Establish Panel					
Create Secretariat					
Orient Members					
Commence Panel, Pre-Meetings, Plan/Finalize Logistics					
Consultations					
Synthesis and Reporting					

Appendix 5: List of Public Consultation Meetings

	Date	Location
1	Nov 29	Kitchener
2	Nov 29	Sarnia
3	Nov 30	Ottawa (French)
4	Nov 30	Ottawa
5	Nov 30	Ottawa - Nepean
6	Nov 30	Owen Sound
7	Dec 4	Ottawa – Vanier
8	Dec 4	Peterborough
9	Dec 4	Newmarket
10	Dec 4	London
11	Dec 5	Brampton
12	Dec 5	Hamilton
13	Dec 5	Toronto – Scarborough
14	Dec 6	Windsor (French)
15	Dec 6	Windsor
16	Dec 7	Mississauga
17	Dec 7	St. Catharines
18	Dec 11	Toronto – Etobicoke
19	Dec 11	Cornwall (French)
20	Dec 11	Cornwall
21	Dec 12	Embrun (French)
22	Dec 12	Richmond Hill
23	Dec 13	Toronto – Downtown
24	Jan 22	Kenora
25	Jan 22	Kenora Kinsmen Meeting
26	Jan 23	Thunder Bay Rotary Meeting
27	Jan 23	Thunder Bay

28	Jan 23	Hearst (French)
29	Jan 24	Timmins (French)
30	Jan 27	Scarborough (Ishmali)
31	Jan 29	Kingston
32	Jan 30	Orillia Kiwanis Meeting
33	Jan 30	Toronto 519 Church Meeting
34	Jan 30	Huntsville
35	Jan 30	Sudbury
36	Jan 30	Vanier – Residents Meeting
37	Jan 31	Toronto YMCA – Citizens Meeting
38	Jan 31	Barrie
39	Jan 31	Toronto (Women's Health in Women's Hands)
40	Feb 5	Sudbury (French)
41	Feb 6	Sturgeon Falls (French)
42	Feb 6	Timmins
43	Feb 7	North Bay
44	Feb 7	Sault Ste. Marie
45	Feb 12	Rockland

Appendix 6: Summary of Discussion Group Findings

List of discussion group meetings

	Location/Date	Group	Language
1	Kingston, Nov. 21	General Public	English
2		Seniors	English
3	Toronto, Nov.22	Jewish	English
4		Caribbean	English
5	Timmins, Nov. 23	General Public	English
6		General Public	French
7	North Eastern Nov. 27	General Public	English
8		General Public	French
9	North Bay, Nov. 28	Seniors	English
10		General Public	English
11	Ottawa, Nov.29	Students	English
12		Students	French
13	Mississauga, Dec. 5	Muslims	English
14	Toronto, Dec. 6	Buddhist	English
15		Aboriginal	English
16	North Western, Dec. 7	Aboriginal	English
17		General Public	English
18	Sarnia, January 30	General Public (18-30)	English
19		General Public 30+	English
20	Hamilton, January 31	Organ Donors	English
21		Organ Recipients	English
22		General Public	English
23	Toronto, Feb. 1	Indo, Pakistan/South Asians	English
24		Asian/Chinese	English
25		Hindu	English
26	Peterborough, Feb. 7	General Public (18-30)	English
27		General Public 30+	English
28	Cornwall, Feb. 8	General Public	English
29		General Public	French
Total			4 French meetings; 25 English

Overview of Discussion Group Findings

General summary

The discussion groups made it clear that organ donation is a subject for which there is a widespread lack of awareness and a great deal of misinformation and wrong perceptions.

Participants said the subject is not top of mind and does not have the profile of heart disease or cancer. "We're busy, we're selfish, and we have other things to worry about."

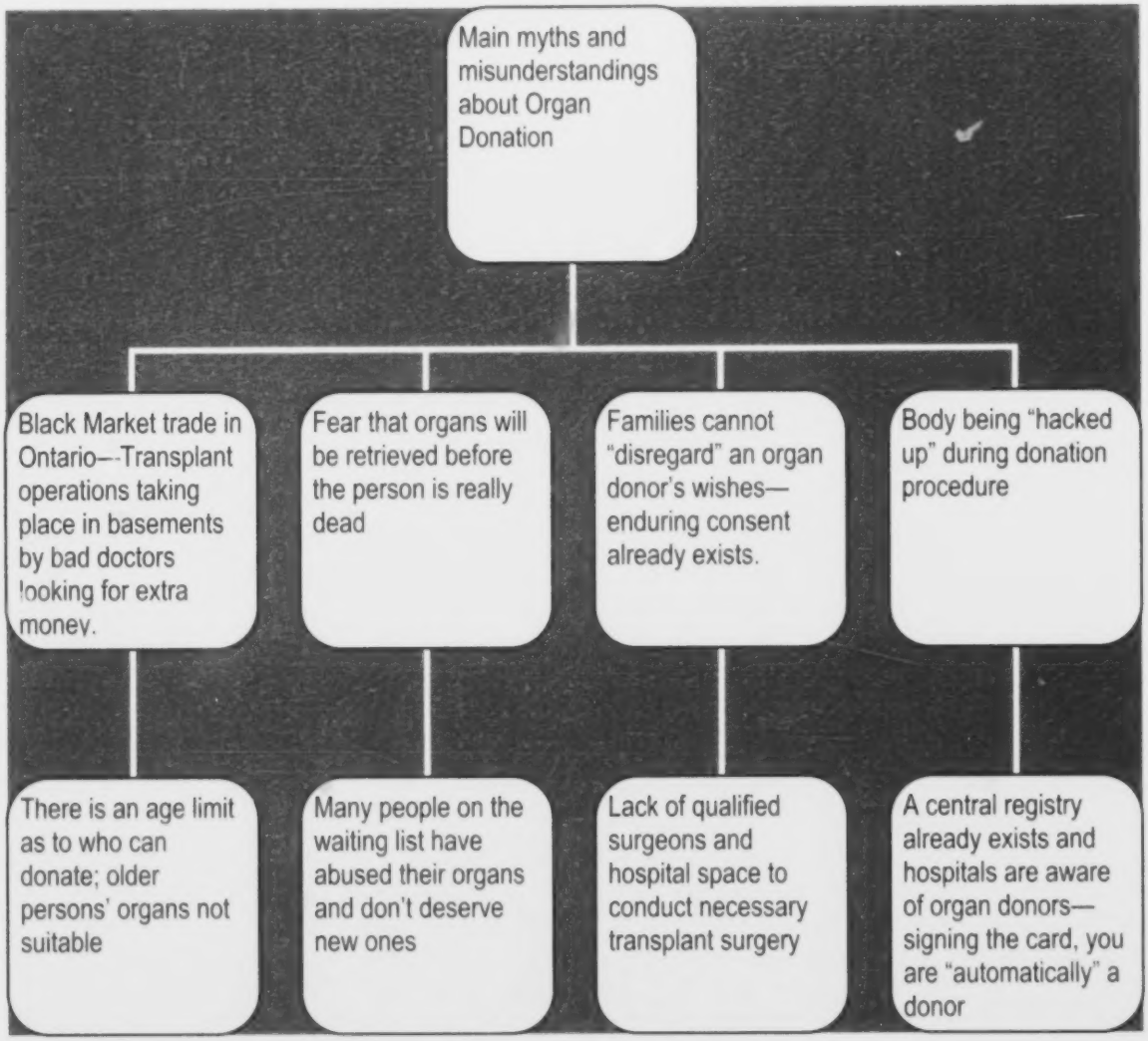
Participants also noted that organ donation was not a comfortable subject for many to speak about because, in their mind, it tempts fate. They also noted that it is the kind of subject that is easier to talk about theoretically, but difficult to deal with when faced with an emotional situation. "In Hungary they say don't (paint) the devil on the wall because it's going to bring pain."

The general 'mystique' around organ donation extends to all sectors within the population: young, old, small town, urban, and across different ethnic groups. This lack of knowledge seems to stem from several things: no coverage of organ donation in the media, lack of education about donation in the schools, no discussion at the political level, and overall reluctance to broach the issue within the family.

This lack of information creates a general sense of confusion, fear and paranoia. It also engenders a feeling of complacency – organ donation is not an issue because there is no information/publicity about it.

Every group called for more publicity about the organ donation situation in Ontario. They wanted information about the number of people on the waiting list versus the number of donors, the types of organs needed, and how more Ontarians need to "step up". Participants wanted an appeal that was very personal, highlighting those waiting for organs, those who had received them, those who had donated and family members who lost loved ones. They called for 'star' power to champion the cause.

Organ Donation - Main Myths and Misunderstandings


Main myths and misunderstandings about Organ Donation
Black Market trade in Ontario—Transplant operations taking place in basements by bad doctors looking for extra money.
Fear that organs will be retrieved before the person is really dead
Families cannot "disregard" an organ donor's wishes—enduring consent already exists.
Body being "hacked up" during donation procedure
There is an age limit as to who can donate; older persons' organs not suitable
Many people on the waiting list have abused their organs and don't deserve new ones
Lack of qualified surgeons and hospital space to conduct necessary transplant surgery
A central registry already exists and hospitals are aware of organ donors—signing the card, you are "automatically" a donor

A Central Registry already exists

Most believed that a central registry already exists, and wanted to be reassured that it would be developed using an exiting system – such as the OHIP registry – under which people could indicate their preferences for organ donation.

Participants also wanted assurances that personal information would be secure and would be updated regularly, with the option to drop out if desired. There were various views on age of consent to become a donor (16, 18, 19 and 21).

There was some skepticism about the cost and the government's ability to effectively implement such a system. The failure of the gun registry was foremost in their minds. However, others said

the government spends money on "silly things", so it should devote funds to something positive like a central organ-donor registry.

Donation Process
The majority opposed adding a question to all government forms. They said it would be a waste of resources and involve too much bureaucracy. They suggested that the box should remain on driver's licenses and OHIP renewals. They also said including it on census, income tax, and life insurance forms, marriage licenses, and hunting and fishing licenses would be acceptable.

Presumed Consent
Participants rejected Presumed Consent, saying it took the giant leap from not hearing about organ donation at all to "everyone is now an organ donor". A number argued it was a violation of civil rights and said this negative option approach was not acceptable in Ontario. The major concern focused on doubts that the government would properly inform everyone, especially new Canadians, those whose mother tongue is neither English nor French, and those with mental disabilities.

Participants called for a more measured approach that would educate Ontarians on the existing situation, outline how they could help and facilitate access to those who have already agreed to be organ donors.

Donor Expenses
A majority of participants wanted the government to cover the expenses of people willing to donate their kidneys or liver, including lost wages, travel and living expenses, child care, and the like.

Young people with no dependents were against compensation, strongly disagreeing with young adults with dependents and older adults over this issue.

Participants agreed the argument comparing the cost of keeping someone on dialysis for a year versus compensating someone for out-of-pocket expenses was very compelling.

Key Differences and Similarities
There were differences of opinion depending on:

- The age of the participants
- Where they lived
- Their religious and ethnic backgrounds. Several religions require that bodies be buried "whole", while others said that it was "good Karma" to give to someone else.

The majority of participants admitted they had no idea of the process for organ donation. Young people knew even less than older adults about the donation process.

Even those who felt their religions "forbade" organ donation said that if their child was in need of an organ transplant, they would opt for this rather than let the child die.

Asian	• Strong tradition of never speaking about death (dying is very personal), and even those Asians who had agreed to be donors, would never speak with family members about it • Older adults very difficult to speak about organ donation • Language a barrier—require translated materials
Aboriginal	• Existing difficulties with literacy rates/public health in their own communities require singular/personal approach apart from forms/websites • Need to work through existing community groups • Because of elevated rates of diabetes within the population, need for organs is high in Aboriginal community
Caribbean	• Concern that new Canadians would not understand system • Belief that live donation results in handicapped donor
Indo/Pakistani	• Approach is not to touch anything relating to the dead person, and if asked about organ donation right after death, the answer would be "no"
Buddhist	• Contradiction between acceptance of death as natural order and giving gift of life • Some schools will donate while others believe it is "bad karma"
Hindu	• Since Hindus are cremated, donating organs is not a problem
Jewish	• Participants turned to "teacher" in group for guidance, suggesting faith-based approach would be most useful
Muslim	• Noted that community would be likely to follow lead of someone with "influence" suggesting faith-based approach would be most useful
Older adults (30+)	• Greater degree of opposition to presumed consent and central registry, especially among the over 50 group. They are fearful information would fall into the wrong hands. • More comfortable speaking about death, with many seniors having prearranged their affairs • Govt. should take a more active role, using advertising as a way of "shaming" Canadians into signing their cards
Young adults (18-30)	• Convinced that "black market" donation is both a reality and a solution to the problem • Lack of understanding of what "brain dead" and "no hope of recovery" really means • More in favour of presumed consent as a way to deal with public apathy, especially within their age group • Not something that is discussed because death is far away/they are immortal • Should be more information available on the web
Smaller centres	• Concern that smaller centres not equipped with infrastructure to support organ donation (doctors, medical facilities, ability to match donors and recipients) • Medical staff in smaller centres not trained on asking families about donation so opportunities are lost
Northern/Rural Ontario	• Legitimate concern regarding viability of organs from rural/Northern communities due to distance

Appendix 7: On-line and mail-back surveys – respondent profiles

The Citizens Panel on Increasing Organ Donations conducted on-line and mail-back surveys on organ donation in Ontario. A total of 2,141 surveys were completed and analyzed.

Of those who completed the surveys:

- 37% said they were very familiar with organ donation in Ontario
- 47% said they were somewhat familiar
- 14% said they were not very familiar
- 2% said they were not at all familiar
- 66% were female; 34% were male – this is an over-sampling of females, as Ontario's population is split 48% male and 52% female
- 10% were 65 or older
- 23% were between 55 and 64
- 26% were between 45 and 54
- 18% were between 35 and 44
- 15% were between 25 and 34
- 7% were between 19 and 24
- 1% were between 16 and 18
- 44% had university and post-graduate degrees
- 41% had some post-secondary education
- 13% had high school or less education
- 41% lived in Southern Ontario
- 23% lived in the Greater Toronto Area
- 13% lived in Eastern Ontario
- 13% lived in Northeastern Ontario
- 9% lived in Northwestern Ontario

Findings of on-line and mail-back surveys:

- 75% who said they were familiar with organ donation had signed their donor cards
- 57% who said they were not familiar with organ donation had not signed their donor cards
- 77% who said they were familiar with organ donation had advised their next of kin about their wish to donate their organs upon death
- 59% who said they were not familiar with organ donation had not spoken to their next of kin about their organ donation wishes
- 41% were not sure if Ontario's current organ donation system is working
- 42% felt Ontario's current organ donation system is not working
- 17% felt Ontario's current organ donation system is working
- 84% said not enough organs are available to match the need

- 77% said they believe waiting lists for organs are very long
- 89% said they are more inclined to donate an organ to a loved one
- 83% said they would donate an organ to a stranger
- 92% of those familiar with organ donation said that their family would respect their wishes
- 84% of those not familiar with organ donation also said their family would respect their wishes
- Generally, respondents agreed that the organ donor retrieval process would be done with respect
- 55% of respondents said they believed there were not many transplants completed in Ontario last year
- 32% said they did not know how many transplants were completed in Ontario last year
- 77% said they did not know whether half the organ donors in Ontario were live donors. Both these responses indicate a lack of information about what is happening with organ donation in Ontario
- 10% of respondents said they believed there were enough potential organ donors in Ontario, but not enough hospital time or doctors to complete the transplant process
- 55% of those not familiar with organ donation had more concerns about barriers to personal organ donation
- 46% of those familiar with organ donation had fewer concerns about barriers to personal organ donation
- 32% said the cost of travel and time off work involved in a "live" donation is a major concern and barrier to personal organ donation.

Of those not familiar with organ donation:

- 31% said **not thinking about organ donation** was a potential barrier compared with 11% of those familiar with organ donation
- 29% of those not familiar with organ donation said **not being aware of which organs can be used** in organ transplant was a potential barrier, compared with 14% of those familiar with organ donation
- 26% of those not familiar with organ donation said a barrier was the fear that **organs might be retrieved before death**, compared with 14% of those familiar with organ donation who cited this as a barrier
- 18% of those not familiar with organ donation said not knowing how one goes about donating organs is a potential barrier compared with 6% of those familiar with organ donation
- Only 3% of all respondents indicated that it might be against their religious beliefs, indicating **this is not a significant barrier** to organ donation in Ontario
- 48% of those not familiar with organ donation said they had concerns about making the decision to donate another family member's organs on his or her behalf compared with 36% of those familiar with organ donation who cited this.

Respondents cited two related concerns over donating organs on behalf of a family member:

1. Lack of awareness of the family member's wishes

2. Not wanting to take responsibility for such a major personal decision

    - 60% of those not familiar with organ donation and 37% of those familiar with organ donation said not knowing the wishes of close family members was a major barrier
    - 38% of those not familiar with organ donation and 22% of those familiar with organ donation said not wanting to make a decision on a family member's behalf was a major barrier

- Respondents rejected other scenarios as being potential barriers. They included:
    - If they were aware of a signed donor card, they would not inform the hospital
    - If they were aware of a signed donor card, they would refuse permission
    - It is against people's religious beliefs
    - Fear that organ donation would interfere with funeral arrangements

- 88% of respondents said it is up to the individual to have the final say on organ donation
- 7% said the family should have the final say; 5% said the power of attorney should rule, and 1% said legal guardians should make the final decision

- Respondents said the five best ways to get people to indicate their consent to donate are through:
    - Donor cards (50%)
    - Increased education (50%)
    - Including it in their will (50%)
    - Presumed Consent (50%)
    - A registry/database (43%)

However, when Presumed Consent was explained as "the hospital would assume you wish to donate organs and want them used for transplant unless you have registered your refusal to donate":

- 51% of those unfamiliar with organ donation rejected this approach and 40% strongly rejected this approach
- 41% of those who said they were familiar with organ donation rejected this approach and 28% strongly rejected this approach

In summary, those not familiar with organ donation – arguably the majority of Ontarians - reject Presumed Consent saying it takes away the individual's right to choose.

Respondents called for more public education about organ donation, including the need for organs, the process for donation, and the ways in which people can indicate their desire to donate.

Respondents also supported the idea that enduring consent – upholding the wishes of those who agree to donate their organs upon their death – is the preferred donation method.

Appendix 8: List of Submissions, Public Inquiries and Presentations to the Citizens Panel

Submissions, Suggestions and Comments

DATE	Topic
Nov 26th, 2006	Ways to increase Organ donations
Nov 26th, 2006	Happy that the Panel exists
Nov 27th, 2006	Massive education campaign and legislate Presume Consent
Dec 4th, 2006	Getting the Hospitals and Health care professionals in small rural communities
Dec 4th, 2006	Having a Proper Database
Dec 4th, 2006	Having a Donor on the Panel
Dec 4th, 2006	Organ donations should be automatic unless you say no
Dec 5th, 2006	Cover funeral costs of donor and work on changing the law in regards to family is not charged for final amount
Dec 5th, 2006	Ask to be a donor when renewing drivers license and OHIP Cards
Dec 5th, 2006	Renewal with drivers and OHIP does not work, against negative consent
Dec 6th, 2006	Awareness is important
Dec 7th, 2006	Donation forms in newspapers
Dec 7th, 2006	Not enough Physicians
Dec 8th, 2006	Fear of Harvesting
Dec 9th, 2006	Permission/Acceptance of the family
Dec, 11th, 2006	Heart Recipient willing to share on certain aspects
Dec, 16th, 2006	Unless stated on Licence Organs should be harvested
Dec 16th, 2006	Presumed consent
Dec 18th, 2006	Presumed consent
Dec 19th, 2006	Central Database
Dec 18th, 2006	Awareness and Promotion of Organ donation
Dec 28th, 206	Fund for funerals should be legislation
Jan 1st, 2007	Next of Kin be added to the Registry form
Jan 2nd 2007	Revise OHIP and Drivers Licence, current not working
Jan 3rd, 2007	Make it law that next of kin should be notified
Jan 4th, 2007	A Donor Plan
Jan 10th, 2007	Ready to Register

Jan 11th	Position Statement on Organ donation
Jan 18th, 2007	Education in Hospitals
Jan 19th	In favour of Automatic organ donation
Jan 19th, 2007	Presentation and Documents regarding Bill 33,
Jan 19th, 2007	Request of Written presentation made by Public
Jan 20th,2007	Support materials for donor families
Jan 20th,2007	Healthcare in Gov't and OMA responsible for waiting list
Jan 22nd,2007	Education in schools on organ donation better than sex education
Jan 23rd, 2007	Sent articles on organ donation
Jan 24th, 2007	Should have a law stating your consent to transplant
Jan 24th, 2007	In favour of Automatic organ donation
Jan 24th, 2007	Against family having the right to override decision
Jan 26th, 2007	Sticker on Drivers Licence
Jan 27th, 2007	Need to change policy and reverse it
Jan 29th,2007	In favour of reverse-onus model
Jan 2nd, 2007	revise OHIP and Drivers licence, current not working
Jan 30th, 2007	Addition notes to the submission presented on Jan 30
Jan 30th, 2007	Article on caring for the needs of the donor family
Jan 30th, 2007	Shared the financial struggle his family went through to help his son who gave him a kidney
Jan 30th, 2007	More awareness is needed
	Suggested Info be available at doctors office and tied in with OHIP card
	Education- Would like to see hospital staff trained to seek organ donations
Feb 1st, 2007	Info on TGLN
Feb 1st, 2007	Email On strategy
Feb 2nd, 2007	No Financial support to support communities
Feb 4th, 2007	Living donors and family priority
Feb 9th, 2007	Sent us a copy of a fax that he sent to someone from the Kidney Foundation that read his presentation
Feb 6th, 2007	Opposed to presumed consent
Feb 6th, 2007	Suggestions on Organ Donation
Feb 9th, 2007	Suggestions on Organ Donation
Feb 9th, 2007	sent answers to the panels question
Feb 22nd 2007	Grief Therapy

Public Inquiries

The Citizen Panel engaged members of the public of Ontario through a number of strategies including hosting 45 public consultations, 29 discussion groups, providing information through website, emails, 1-800 Number and to our offices. Members of the public used all these communication channels which were accessible to them around the clock and made many comments and suggestions.

The website and hotline was made available to the public with the announcement of the Panel by Minister Smitherman on 24th November 2006. The website and its attached email has been a portal of information that has aided the panel in their recommendations. The website received 7000 visits, just under 150 unsolicited emails, and over 360 postal and electronic addresses for people that have subscribed to our mailing list and interested in receiving further updates and the report.

The offices of the Panel and the Ministry of Health and Long Term Care's toll free number received over 500 calls. The calls ranged from the public wishing to submit comments, suggestions, proposals, volunteering services and general inquiries.

Presentations to the Citizens Panel

Date	Name	Title, Organization	TOPIC
Oct, 26, 2006	Sue Wilson Frank Markel	Chair, Board of Directors, Trillium Gift of Life Network (TGLN) President and CEO, Trillium Gift of Life Network	TGLN Mandate
Nov, 17, 2006	Kim Young Beverly Curtis	Chief Executive Officer, CCDT Incentives Director	Activities of the CCDT Approaches to diverse communities Key research with frontline providers in health sector
Nov, 17, 2006	Dr. Frank Markel	President and CEO, Trillium Gift of Life Network	Hospital by Hospital by Organ Donation Programs
Dec 15,2006	Carol Payne	Trillium Gift of Life Network	Waiting lists
Jan 11, 2007	Rev. Ken Beal	Retired Director of Pastoral Care	Kitchener Hospital
Jan 12, 2007	Dr. William Wall	Director of Multi-Organ Transplant Program	Education / London Program

Jan 12, 2007	John Oliver	Senior Communication and Policy Adviser, UK Transplant	Update on UK
Jan 19, 2007	Honourable Dave Levac	M.P.P. Brant, Chief Government Whip	Private members Bill 33
Jan 19, 2007	Jennifer Tracy Dr. Frank Markel	Director of Public Affairs, Trillium Gift of Life Network President & CEO, Trillium Gift of Life Network	Communications Promotion
Jan 19, 2007	Susan Pinney Timothy Scott	Sr. Manager Registration Program (OHIP) Manager, Registration Services	OHIP/Registry
Feb 2, 2007	Graham Scott, QC	Senior Partner, McMillan Binch, Former Deputy Minister	
Feb 2, 2007	David Fleming	Executive Director, Donate Life – Organ Donation & Transplant Breakthrougn Collaborative	Registries in the USA
Feb 2, 2007	Virginia McBride Dr. Mary Ganikos	Public Health Analyst OPTN Project Officer Division of Transplantation, Health Resources and Services Administration Chief, Education Branch, Division of Transplantation, Health Resources and Services Administration	Collaborative in the USA
Feb 2, 2007	Lorraine Gerrard Ken Donohue	Executive Director, Kidney Foundation Canada Communications Manager, BC Transplant	Living Organ Donor Expense Reimbursements Program in BC
Feb 9, 2007	Mance Cleroux	Executive Director, Quebec Transplant Program	Update on Quebec
Feb 9	Dr. Pagliarello	Hospital Transplant Co-oordinator, Ottawa Hospital	Public awareness on donor Issues
Feb 9	Dr. Sam Shemie	Medical Doctor, Extracorporeal life Support Program, Montreal Children's Hospital McGill University Health Centre	
Feb 9	Dr. Stewart	Director of ICU – UHN and Mount Sinai Hospitals	Donation after cardiac death

Appendix 9: Report Card of Previous Recommendations, Provincial and Federal

Legend
N – not recommended
Y – recommendation made

PROVINCIAL - CENTRAL AUTHORITY

Recommendations	Task Force on Kidney Donations (1984 MOH)	Provincial Task Force on Organ Donation – Retrieval and Distribution (1984 MOH)	Organ & Tissue Donation in Ontario – A Plan for Change and Action (2000)	Organ Donation: Crisis in Ontario – Finding Solutions (2006 symposium)	Ready to Register (2006 Ontario)	Trillium Gift of Life Network Initiatives (2006/2007)	**Current status of previous recommendations in Ontario**
Establishment of province-wide overseeing agency to receive $ from Government of Ontario	N	Y	Y	N	N	N	**Action taken (establishment of TGLN, 2000, Government on Ontario)**
Establishment of central registry system, available 24/7	Y	Y	Y (to be modelled using evidence from models in BC & Nova Scotia)	Y	Y	N	**No action taken**
Establishment of real-time waiting lists	N	N	N	N	N	N	**No action taken**

PROVINCIAL - EDUCATION

Recommendations	Task Force on Kidney Donations (1984 MOH)	Provincial Task Force on Organ Donation – Retrieval and Distribution (1984 MOH)	Organ & Tissue Donation in Ontario – A Plan for Change and Action (2000)	Organ Donation: Crisis in Ontario – Finding Solutions (2006 symposium)	Ready to Register (2006 Ontario)	Trillium Gift of Life Network Initiatives (2006/2007)	**Current status of previous recommendations in Ontario**
Increased/ongoing public education, promotion, PSAs	Y	Y	Y (incld within gr. 11 curriculum & development of donor cards & emphasis on living donors)	Y	Y	Y	Ongoing efforts (high school curriculum program in force in London only), needs improvement
Toll-free information # available	N	Y (originally with MORE, now defunct)	N	N	N	N	Needs improvement
Donor community recognition/appreciat-ion	N	N	Y	N	N	N	Needs improvement
Ongoing program of education for health-care staff	Y	Y	Y	Y	Y	N	Needs improvement
Faculties of Medicine in Ontario include transplant education program	N	Y	N	N	N	N	Needs improvement/no action taken

PROVINCIAL - POLICY

Recommendations	Task Force on Kidney Donations (1984 MOH)	Provincial Task Force on Organ Donation – Retrieval and Distribution (1984 MOH)	Organ & Tissue Donation in Ontario – A Plan for Change and Action (2000)	Organ Donation: Crisis in Ontario – Finding Solutions (2006 symposium)	Ready to Register (2006 Ontario)	Trillium Gift of Life Network Initiatives (2006/2007)	**Current status of previous recommendations in Ontario**
Routine notification & request (RNR)	N	N	Y	N	Y	Y	**Action taken**
Donation after cardiac death (DCD)	N	N	N	N	Y	Y	**Action taken**
Coverage of all living donor expenses	N	Y	Y	Y	N	N	**No action taken**
Required response (connected to OHIP/drivers licence)	N	N	N	Y	N	N	**No action taken**
Presumed consent	N	N	N	Y	N	N	**No action taken**

PROVINCIAL - IN HOSPITALS

Recommendations	Task Force on Kidney Donations (1984 MOH)	Provincial Task Force on Organ Donation – Retrieval and Distribution (1984 MOH)	Organ & Tissue Donation in Ontario – A Plan for Change and Action (2000)	Organ Donation: Crisis in Ontario – Finding Solutions (2006 symposium)	Ready to Register (2006 Ontario)	Trillium Gift of Life Network Initiatives (2006/2007)	Current status of previous recommendations in Ontario
Mandate in hospital policy to encourage and provide guidelines for transplants/donation	Y	Y	Y	Y	N	N	Variable amongst hospitals
Organ retrieval co-ordination team designated within/to hospitals, including training	Y	Y	Y	Y	N	Y	Variable amongst hospitals
Alongside medical staff: chaplains/social services be integrated as participants in process, especially in regards to donor family needs	N	Y	N	Y	N	N	Variable amongst hospitals

Improved remuneration for physicians/hospitals active in donor assessment/trans-plant process	Y	Y	Y	Y	Y	N	Some action taken
Ongoing audits/tracking of hospital deaths/donation rates	Y	Y	Y	N	N	N	Action taken

FEDERAL - CENTRAL AUTHORITY

Recommendations	Organ and Tissue Donation and Distribution in Canada (1996 FPT Ministers of Health)	A Co-ordinated and Comprehensive Donation and Transplant Strategy for Canada (1998 FPT Advisory Committee on Health Services)	Organ and Tissue Donation and Transplantation: A Canadian Approach (1999 Report of the Standing Committee on Health)	National Recommendations for Donation after Cardio circulatory death in Canada (2006 CMAJ)	**Current status of previous recommendations in Ontario**
Establishment of National program – pan-Canadian system	Y (formalized national sharing programs)	Y (CCDT, est. 2001 to provide advice, non-profit as of 2005, focus to effect change)	Y	N	**Ongoing efforts (the CCDT provides much need statistical information, needs also to act as a national unifier)**
Establishment of central registry system, available 24/7	Y (national tracking system to match donors and recipients)	Y	Y	N	**No action taken**
Establishment of real-time waiting lists	N	N	Y	N	**Not recommended**

FEDERAL - EDUCATION

Recommendations	Organ and Tissue Donation and Distribution in Canada (1996 FPT Ministers of Health)	A Co-ordinated and Comprehensive Donation and Transplant Strategy for Canada (1998 FPT Advisory Committee on Health Services)	Organ and Tissue Donation and Transplantation: A Canadian Approach (1999 Report of the Standing Committee on Health)	National Recommendations for Donation after Cardio circulatory death in Canada (2006 CMAJ)	**Current status of previous recommendations in Ontario**
Increased/ongoing public education, promotion, PSAs	Y	Y	Y	Y	Ongoing efforts, needs improvement
Toll-free information # available	N	N	N	N	**Not recommended**
Donor community recognition/appreciation	N	N	Y	N	**Needs improvement**
Ongoing program of education for health-care staff	Y	Y	Y	Y	Ongoing efforts
Faculties of Medicine include transplant education program	N	Y	N	N	Needs improvement/no action taken

FEDERAL - PRACTICES

Recommendations	Organ and Tissue Donation and Distribution in Canada (1996 FPT Ministers of Health)	A Co-ordinated and Comprehensive Donation and Transplant Strategy for Canada (1998 FPT Advisory Committee on Health Services)	Organ and Tissue Donation and Transplantation: A Canadian Approach (1999 Report of the Standing Committee on Health)	National Recommendations for Donation after Cardio circulatory death in Canada (2006 CMAJ)	**Current status of previous recommendations in Ontario**
Routine notification & request (RNR)	N	N	N	N	**Action taken (as a result of TGLN & OPO initiatives)**
Donation after cardiac death (DCD)	N	N	N	Y	**Action taken**
Coverage of all living donor expenses	N	N	N	N	**Not recommended**
Required response (connected to OHIP/drivers licence)	N	N	N	N	**Not recommended**
Presumed consent	N	N	N	N	**Not recommended**

FEDERAL - IN HOSPITALS

Recommendations	Organ and Tissue Donation and Distribution in Canada (1996 FPT Ministers of Health)	A Co-ordinated and Comprehensive Donation and Transplant Strategy for Canada (1998 FPT Advisory Committee on Health Services)	Organ and Tissue Donation and Transplantation: A Canadian Approach (1999 Report of the Standing Committee on Health)	National Recommendations for Donation after Cardio circulatory death in Canada (2006 CMAJ)	**Current status of previous recommendations in Ontario**
Mandate in hospital policy to encourage and provide guidelines for transplants/donation	Y	Y	Y	Y	Variable amongst hospitals
Organ retrieval co-ordination team designated within/to hospitals, including training	Y	N	N	N	Variable amongst hospitals
Alongside medical staff: chaplains/social services be integrated as participants in process, especially in regards to donor family needs	N	Y	Y	N	Variable amongst hospitals

Improved remuneration for physicians/institutes active in donor assessment/transplant process	Y	Y	Y	N	**Variable amongst hospitals**
Ongoing audits/tracking of hospital deaths/donation rates	N	Y	Y	N	**Variable amongst hospitals**

Summary
The 1999 establishment of the Trillium Gift of Life Act and the subsequent 2000 publication, Organ and Tissue Donation in Ontario, A Plan for Change and Action, have been both a catalyst and leader in the increasing efforts to address the shortcomings of the transplant and donation system in Ontario.

Because it identified key issues in improving organ donation and transplantation, A Plan for Change and Action has become a handbook of sorts for health-care professionals in Ontario. However, many of the requirements and recommendations made at that time, sadly, seven years later, correspond almost exactly to the findings and recommendations of the Panel today.

In addition to addressing the lack of action taken on a number of central issues relating to this topic, it must also be pointed out that the 2000 report and those undertaken in the following years must be commended for they have produced several shining examples of usable and realistic legislation and policy that have had lasting positive results.

These include the establishment of the Trillium Gift of Life Network, the instatement of Routine Notification and Request (RNR), the passing of law that makes donation after cardiac death (DCD) acceptable, and the most recent which creates accountability through ongoing audits and tracking of hospital death and donation rates. The Panel has seen that such efforts have created a solid support base from which these positive changes gain momentum and begin to enter the public consciousness.

However, it must be said that these progressive examples – while undoubtedly amplifying the considerable efforts and achievements of those active in this field (see report card of recommendations, current status of previous recommendations in Ontario – action taken) – also serve to shine a harsh light on those issues where Ontario consistently is struggling and which need urgent attention.

The most notable example of this is the need for establishment of a central database – a recommendation that has been in effect since two separate 1984 publications from the Task Forces on Kidney Donation and Organ Donation, Retrieval and Distribution. For more than 20 years, the province has been slowly attempting to build a usable system. However, this format has had no central repository that can be accessed – by both public and health-care professionals - nor actively monitored, so that gaps and shortfalls can be quickly dealt with.

The Panel recognizes the vital need to actively pursue and support plans of action that are realistic, progressive, and specific to the needs of Ontario. There is an untapped amount of potential in these recommendations and it is potential that has the ability to create long-term change. Ontario has an opportunity to assume a national role and it is hoped that by applying the best practices that have been learned from other organizations in this field – and utilizing them in combination with a uniquely Canadian system – we can set a countrywide – and possibly even global – example. More importantly, we can begin to answer the need of people in our own community's who are surely struggling with both their illness and their frustration with this defective system.

Appendix 10: Registry/Database and Costing

	British Columbia	California	Utah	UK
Technology development, implementation, systems management planning	$234,196*		$75,000 - $200,000 (US)**	£200,000 per year (ongoing costs include database, verification of applications, correspondence)***
Initial software development	$60,000	$40,000 - $50,000 (US)	$40,000 - $60,000	
Communications, planning and launch	$504,600	$70,000	Approx. $1,000,000 over 3-year period as of 5 years ago	£1,000,000 annually (department budget)
Ongoing education/public awareness			$150,000 - $160,000 (annually)	

* Osborne Margo Registry Report submitted to TGLN
** Tracy Schmidt – executive director, Intermountain Donor Services, Utah
*** Dominic Moody – Media & Public Relations Officer, UK Transplant

The models cited provide an approximation of the registry costs that might be expected by the province and can be broken down into three main categories: Before – technology development and systems planning; During – communications material and project launch; and After – ongoing expenses and maintenance of the registry. The majority of expenses are incurred in the Before and During period of the establishment of a registry. Across the board, a one-time amount of approximately $200,000 – $250,000 is required to create the system in addition to a one-time amount of approximately $40,000-$60,000 for communications and launch. Once the registry is up and running, the yearly cost decreases from about $150,000 as the registry becomes established and gains momentum. The initial costs for planning and launch are minimal when compared with the return and ongoing community value received by having the registry.

Appendix 11: Religious Viewpoints on Organ Donation and Transplantation

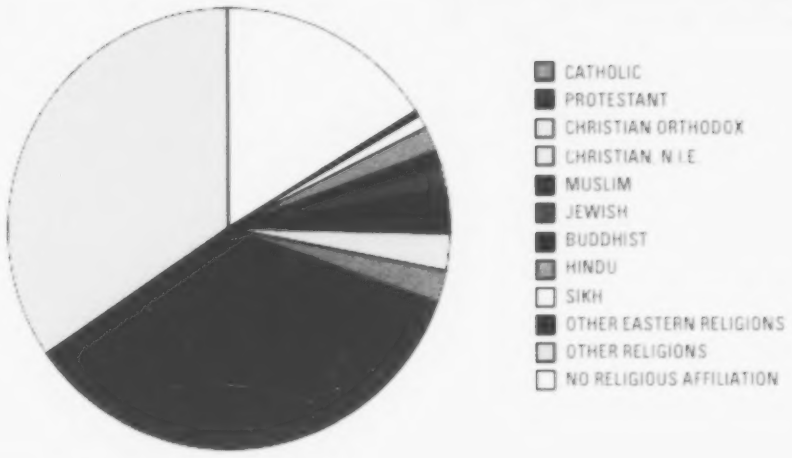
Canada's population is constantly growing in diversity with numerous ethno-cultural communities from around the world represented. By 2017, it is predicted that 23% of Canadians will identify themselves as "racially visible" and 4% will be members of the rapidly growing Aboriginal community. Overall, the largest racially visible communities will be Chinese, South Asians and Afro-Canadians. As a result, in cities such as Toronto and Vancouver certain ethno-cultural communities will form the majority of the population (CCDT, Discussion with Chinese Canadians, Toronto, 2005, pg. 2). With the largest and most multi-cultural provincial population in Canada, Ontario has a particular responsibility to encourage the education of itself and its citizens in cultural sensitivity, inclusion and awareness with regards to organ donation and transplantation.

In Ontario, the Trillium Gift of Life Network has continuously recognized the importance of drawing attention to and making information available regarding faith views on organ donation and transplantation. Trillium has consistently operated with the knowledge that culture and religion play a significant role in end-of-life experiences, including how people respond to illness, how grief is demonstrated, what rituals are important at death, and which members of the family are present. Also, it is a time when a family's religious views/leader are likely to be very involved, and sought after for advice and counsel. During this time, people may be particularly careful not to violate faith dictates and still many more people may not explore their personal religious beliefs until they are dealing directly with a health crisis, either their own or a member of their family.

However, because of the routine notification request initiated within hospitals in Ontario, every patient and/or family with the potential to make a gift of life decision will be approached and Trillium has long been committed to ensuring that they have access to multi-faceted information in order to help make an informed decision that is appropriate to them. Currently, pamphlets outlining religious views on organ donation are available by specific request and from transplant co-ordinators within the hospital itself. In addition to this, Trillium is in the process of attempting to establish a 24-hour hotline – that can be accessed by families – and puts them in contact with various faith leaders and authorities.

These efforts are made in recognition that ethno-cultural and faith-based information comes not only from organ-procurement organizations, but also from faith leaders themselves. As such, every opportunity must be made to encourage direct dialogue between faith leaders and the individuals and families within their congregations. If respectful processes are followed the majority of religions either openly endorse organ donation or respect that it is an individual's personal choice (www.giftoflife.on.ca, February 11, 2007). As such, for organ donation and transplantation to reach optimal levels, religions must be educated in – and willing to champion – this cause, and to encourage it within their congregations (Faith Perspectives on Organ and Tissue Donation and Transplantation, CCDT, pg. 1).

Following is a compilation of faith views and statements on beliefs regarding organ donation and transplantation as represented in Ontario's multi-ethnic mosaic:



(Source: Statistics Canada)

Aboriginal – The donation of vital organs is not generally acceptable to traditional practitioners. Those community members that are Christian believe the decision to give or receive organs is permitted. Aboriginal peoples are the fastest growing population in Canada and are experiencing an increase and revitalized focus on reclaiming indigenous thought and practice, traditional beliefs and wisdom including distinct tribal customs that are seen as necessary to clear the path to the spirit world (Diane Longboat – conference, January 31, 2007, Toronto – Aboriginal Perspective in Ontario). This will undoubtedly include the involvement of family, community and Elders in guiding decision-making (CCDT, Diverse Communities: Perspectives on Organ and Tissue Donation and Transplantation, pg. 6, 2005).

Asian – It should be noted that the greatest number of newcomers to Toronto and Ontario are from China and that a growing number of Chinese Canadians are in need of organs (particularly liver). With suitable matches more likely to be found among people with similar biological traits or from the same racial or ethno-cultural background it is important that this community discovers a potential role for itself in helping to ease the need of its affected members (CCDT, Diverse Communities: Consultation to Explore Peoples' Views on Organ & Tissue Donation, Discussion with Chinese Canadians, pg. 1, Toronto, 2005). Elder generations may exhibit strong reluctance to the ideas of disturbing the body because of an enduring tradition of filial piety/ancestor worship. As a result, it may be found that implicit references to death by healthcare professionals can complicate discussions with the family (Timothy Rice, conference, January 31, 2007, Toronto – Asian perspectives and patient care in the ICU); however, evolving views towards acceptance of donation amongst those born in Canada are present.

Buddhism - Buddhists have no official position on organ donation as it is widely believed that donation and transplantation is a matter of individual conscience. Donation of organs is seen as an inherently virtuous and life-saving act though organ procurement itself is potentially disruptive (Henry, Blair Buddhism in Ontario. Religious Considerations for Health Care Management within a Critical Care Environment – conference, January 31, 2007, Toronto).

Reverend Gyomay, President and Founder of the Buddhist Temple of Chicago says, "We honour those people who donate their bodies and organs to the advancement of medical science and to saving lives." This matter may be complicated by differences in attitude between the Northern and Southern traditions of Buddhism as tied to the concept of "rebirth" and when it occurs. The Southern tradition permits autopsies and organ transplants, in the belief that rebirth occurs immediately upon death. However, the Northern tradition believes that there is an intermediate state between "incarnations" and avoids movement or touching of the body for eight hours.

Catholicism – The church has openly encouraged and supported donation as an act of charity, a decision that belongs to each individual and one that must be made without undue, external pressures. Certain ethical considerations must be taken into account (e.g., no commercialization of human organs), and "the removal of vital organs" must not take place "until natural death has occurred and been ascertained."

In 1956, Pope Pius XII declared that: "A person may will to dispose of his body and to destine it to ends that are useful, morally irreproachable and even noble, among them the desire to aid the sick and suffering...this decision should not be condemned but positively justified."

In August 2000, Pope John Paul II told attendees at the International Congress on Transplants in Rome: "Transplants are a great step forward in science's service of man, and not a few people today owe their lives to an organ transplant. Increasingly, the technique of transplants has proven to be a valid means of attaining the primary goal of all medicine - the service of human life. There is a need to instill in people's hearts, especially in the hearts of the young, a genuine and deep appreciation of the need for brotherly love, a love that can find expression in the decision to become an organ donor."

Cardinal Joseph Ratzinger, prior to becoming Pope Benedict XVI, described organ donation as being "an act of love … so long as it is free and spontaneous." In a February 4, 1999, interview with the ZENIT International News Agency, Cardinal Ratzinger said that he was a registered organ donor. "To donate one's organs is an act of love that is morally licit, so long as it is free and spontaneous."

Greek Orthodox - The Greek Orthodox Church approves of organ and tissue donation provided they are used to better human life.

According to Reverend Dr. Milton Ffthimiou, Director of the Department of Church and Society for the Greek Orthodox Church of North and South America: "The Greek Orthodox Church is not opposed to organ donation as long as the organs and tissues in question are used to better human life [for example] for transplantation or for research that will lead to improvements in the treatments and prevention of diseases."

Hinduism - According to the Hindu Temple Society of North and South America, Hindus are not prohibited from donation as confirmed by religious laws and this act is seen as an individual's decision.

H. L. Trivedi, in Transplant Proceedings, stated, "Hindu mythology has stories in which the parts of the human body are used for the benefit of other humans and society. There is nothing in the Hindu religion indicating that parts of humans, dead or alive, cannot be used to alleviate the suffering of other humans."

Islam - The religion of Islam strongly believes in the principle of saving human lives as long as the human body is respected and treated with dignity, and the sanctity and protection of human life are paramount. In addition, a person must give the gift of life freely and without undue pressure, for the purposes of saving another life or to enable another person to perform a missing and essential function.

According to A. Sachedina in his Transplant Proceedings article Islamic Views on Organ Transplantation "... the majority of the Muslim scholars, belonging to various schools of Islamic law, have invoked the principle of priority of saving human life and have permitted the organ transplant as a necessity to procure that noble end."

Jainism – The essence of the Jain faith system is non-violence (not to kill or harm any living beings) and a foundational belief in reincarnation, the theory of karma and the transmigration of soul. Their ascetic vow of non-violence means that Jains are strict vegetarians and may also prohibit the receiving of certain medications, blood transfusions and organ transplants. In regards to donation of organs after death the Jain concept emphasizes the importance of saving another's life and this can therefore be considered acceptable to Jains. As there is an absence of any specific yes or no statement in regards to donation it is left to the discretion of the individual. Particular end of life care may include the reading of certain texts to inspire comfort and consolation in the patient in addition to devotional songs, chants and mantras which may also be recited. After death, the body is cremated according to the Jain ritual.

Judaism - All four branches of Judaism (Orthodox, Conservative, Reform, and Reconstructionist) support and encourage donation. The general directive invoked in support of donation and transplantation is that the "saving of a human life takes precedence over all other laws," including any resultant delay in burial. Organ and tissue donation is thus encouraged not only "for humanity's sake," but also "for God's sake, as a supreme expression of Godliness."

The Halachic Organ Donor Society (HOD Society) disseminates information regarding Halachic issues and Rabbinic opinions concerning organ donation. The HOD Society offers card-carrying membership in a society that allows people to donate organs in accordance with their particular Halachic belief.

Protestantism - The Protestant faith respects individual conscience and a person's right to make decisions regarding his or her own body. In addition, it is generally believed that resurrection does not involve making the physical body whole again and thus removal of organs cannot be considered harmful. Death can become seen as a source of hope because Jesus is perceived to have already prepared and blessed the path of birth, death and resurrection.

Shintoism – This faith group generally either openly opposes or is extremely cautious regarding organ and tissue donation particularly because families are concerned that they do not injure the "itai" (the relationship between the dead person and the bereaved family).

Sikhism – Sikhs declare a positive endorsement regarding organ and tissue donation. While Sikh philosophy and teaching places great emphasis on the importance of selfless service to others and the performance of "noble deeds" they also believe that, "the physical body is a temporary abode of a person's soul, and it is the soul that is one's real essence." Thus, their belief regarding the technicalities of reincarnation is such that donation and transplantation does not hinder one's rebirth.

Taoism - No objections to use of part of body after death (www.giftoflife.on.ca, February 9, 2007).

National Donor Sabbath

The National Donor Sabbath is a celebration of organ and tissue transplantation which aims to raise public awareness about transplants and the need for donated organs and tissues. This event is endorsed by the U.S. Department of Health and Human Services. It aims to draw attention to the fact that all major religions support donation, but many families are reluctant to do so as they often do not know their religions' standpoint on this issue. A study in 2002 by the Johns Hopkins School of Medicine and Bloomberg School of Public Health in the journal Medical Care confirmed that religious misconceptions were one of the major reasons why more people, particularly minorities, did not become blood and organ donors.

As participants in the Sabbath, faith communities throughout the country participate in discussions as to how organ and tissue donation can be increased, so that more lives are saved through transplantation. Religious leaders of all faiths are encouraged to receive free materials, ideas for sermons, and other resources for National Donor Sabbath. Religious leaders are also asked to encourage their communities to discuss their wishes regarding donation with their families.

The event is traditionally observed on the Friday, Saturday and Sunday two weeks before the Thanksgiving Holiday, so that the National Donor Sabbath effectively launches the holiday season.

10 Ways Faith Leaders Can Help

1. Encourage discussion about organ and tissue donation in your community now. It is much easier for families to make a decision to donate before they face a crisis.
2. New life arising from death is a common religious theme. When appropriate, talk about donation in your sermons and messages.
3. Lead prayer to remember those families who suffered loss through death, yet offered life through organ and tissue donation. Include the thousands of men, women and children who continue to wait for desperately needed organs and tissues to save or improve their lives.
4. Work with community groups, religious organizations and families to promote public awareness of donation and transplantation.

5. Lead by example: Let your congregation know that you have signed a donor card and discussed the decision with your family.
6. Schedule educational presentations for your congregation's professional organizations. Gift of Hope Organ & Tissue Donor Network will be happy to assist you.
7. Distribute donation information in your community through bulletins and newsletters.
8. Invite a donor family member or transplant recipient to speak during a service, youth class, or adult ministry group.
9. Celebrate National Donor Sabbath with thousands of other congregations throughout the country in November.
10. Sign a donor card and tell your family and/or congregation today.

(Source: http://www.giftofhope.org)

Appendix 12: Presumed Consent

The Panel's survey indicates that 84% percent of respondents know that there are not enough for organs available to meet the need in Ontario. Additionally, opinion polls persistently show that upward of 85% of Ontarians are in favour of organ transplants; a November 2006 poll put that figure at 93%. Still, even though people understand there is a crisis and have no theoretical objection to the solution, getting them to follow through to the next logical step and take action remains a persistent challenge. One proposed model for overcoming this inertia is Presumed Consent.

The current model used in Canada, including Ontario, is Informed Consent – that is, a person or their family must take the decision to donate or it doesn't happen. This is also referred to as an "opt in" system.

Presumed Consent, on the other hand, assumes that everyone wants to donate unless they've registered their objections otherwise. This is also known as opting out.

To date, 24 nations, primarily in Europe, have legislated some form of Presumed Consent. Other jurisdictions, including three U.S. states and Great Britain, have considered the option and rejected it.

An opt-out system can be "hard" as in Austria, where families cannot refuse and their views are not taken into account. All other Presumed Consent nations use the "soft" model where physicians still consult with family members. This gives doctors the opportunity to explain the law to the relatives and to ask them if they know whether the patient had an unregistered objection to organ donation. Panel research shows physicians do not proceed with organ retrieval against a family's objections on any grounds.

Statistics are not conclusive as to the effectiveness of Presumed Consent. Some countries have donation rates that are higher than where informed consent is the norm, others are well below (see Chart 7).

The topic of Presumed Consent stirred up some of the liveliest debates at the Panel's public consultation meetings and in the discussion groups. The Panel's survey also reflects the strong passions the concept evokes. Only seven per cent of respondents indicated they are neutral on the topic.

Participants in the two groups put forth many arguments that would be familiar to legislators, medical associations, patients group and academics the world over that have grappled with this contentious issue.

Proponents look at the issue through the lens of need and argue along lines of utility: Given that the majority of people would be willing to donate, but are too apathetic / busy / lazy to make their decision known, Presumed Consent most likely reflects their wishes.

Those opposed consider the issue through the lens of personal autonomy and argue that the state has no right to assume it is entitled to take their organs.

In addition, there were some particularly Canadian arguments put forth in the groups. One woman noted that Canadians care enough to fund a universal health-care system and claimed that Presumed Consent is simply a further reflection of this generosity.

Among those opposed, another peculiar Canadian argument arose. Participants in several sessions made spontaneous comments comparing opting out to "negative option billing." This is a reference to the 1995 attempt by a large cable systems operator to automatically bill for new cable specialty channels being introduced that year unless customers specifically said they did not want them. A massive consumer revolt forced the company to back down and charge customers only for the channels they had asked for.

Of the three research modalities, the Panel believes that in this instance, the discussion groups are the truest reflection of what Ontarians in general want. The public consultation meetings and the survey allowed for self-selection and, not surprisingly, those already attached are over-represented.

Conversely, discussion group participants were chosen at random using a scientifically-accepted model to reflect the overall population. It was in these groups that opposition to Presumed Consent was clearest and strongest. They feared that Presumed Consent would change the very nature of organ donation.

In Ontario, organ donation is a gift from one person to another of a vital organ. By definition, giving a gift is a positive – and freely taken – step. But with Presumed Consent the organ is no longer given, it is taken. It would not take much of leap, participants said, for the public to perceive this as organ harvesting.

The Citizens Panel shares their concerns. Furthermore, we are concerned that this perception could lead to a loss of confidence in Ontario's organ-donor system and to the practice of medicine as a whole.

The Panel appreciates how strongly those in favour of Presumed Consent hold their views, and understands that depth of feeling is often borne of frustration with the seemingly intractable gap between the need and availability of organs. The Panel, however, does not accept the argument that Presumed Consent will give the people Ontario what they want.

Furthermore, the Panel does not accept that registering their objections is sufficient protection for those who do not want to donate. Indeed, the very argument that proponents use in favour of Presumed Consent – that it overcomes the inertia – is more appropriately an argument against.

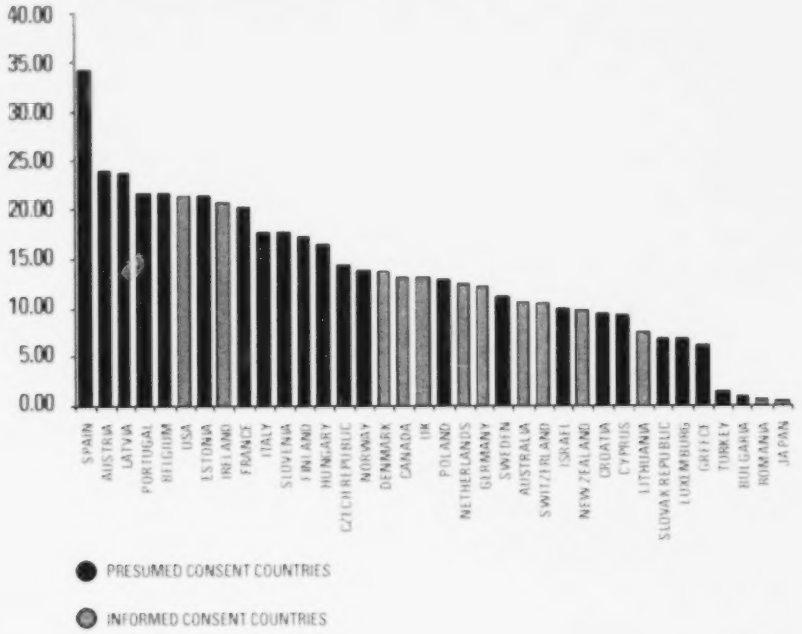
Population statistics do not apply at the level of the individual. We cannot know whether a person's lack of a registered objection is implicit consent or that they simply never got around to it. It may

also indicate a lack of knowledge about how to opt out or even reflect the fact the individual lacked the understanding or capacity to make an informed decision.

Conclusion

Given that physicians in most Presumed Consent countries still consult with and accede to the wishes of the family, and given that an opt-out registry is too passive a method to be a clear statement of an individual's intent, the Citizens Panel concludes that Presumed Consent cannot ensure Ontarians their No. 1 priority concerning organ donation: that their wishes alone be respected. Furthermore, given the corrosive nature of the debate and the fact that there is no consensus on its effectiveness, the Citizens Panel recommends against enacting Presumed Consent legislation.

Chart 7: Cadaveric Donation Rates in 2002



Source: The Impact of Presumed Consent Legislation on Cadaveric Organ Donation: Cross-Country Survey. Alberto Abadie and Sebastien Gay
http://ksgnotes1.harvard.edu/Research/wpaper.nsf/rwp/RWP04-024/$File/rwp04_024_abadie.pdf
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